Gathering Momentum: Mobilizing to Transform Community Living in BC

L'Institut Roeher Institute

Researched and Written by
Cameron Crawford

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Executive Summary

This report discusses the transformation of community living services in British Columbia from May 2001 until January 2003. The study investigated the work of a coalition of people who came together to organize for improved services to people with developmental disabilities. Their work and later that of the Transition Steering Committee led to the creation of the Interim Authority for Community Living British Columbia (CLBC). CLBC is the new provincial authority that is being created to manage the support system for people with developmental disabilities.

In preparing this report, researchers from the Roeher Institute interviewed 47 individuals and reviewed key documents and minutes provided by the Interim Authority and others who participated in the study. Interviewees came from a wide cross section of the community including the Ministry of Children and Family Development (MCFD), the Interim Authority (IA), service providers, families and self advocates. A diversity of voices was purposely sought.

The Board of the Interim Authority for Community Living British Columbia supported this research with the intent of documenting the process of its inception and uncovering points of tension that needed to be addressed as the Interim Authority carried out its work. As process evaluation, the aim of this paper is to inform the actions of the people working to transform community living with feedback from the community involved.

The Context

The BC Liberals came to power in a landslide victory in May 2001. The new government moved forward with an aggressive agenda that included major fiscal restraint and the devolution of some key responsibilities from government to other authorities.

The Core Services Review, Ministry Service Plans and budgetary responses to the looming provincial deficit spurred family members, other community activists and service providers into action. While the government's intended directions presented potential risks to people with developmental disabilities and their families, activists recognized that there were new opportunities to reform a community living services system that was in crisis and unsustainable.

The post-institutional era of plenty for that system was over. There was little new money for community living services, yet the demand for service continued to escalate year after year. Funding was channelled mainly to issues of child protection and the most serious cases of health and safety. Per person costs approaching $60,000 per year were high and in some cases were three to five times that rate.

People with similar needs received dissimilar levels of funding and service. Many received nothing at all and the wait lists were growing. While there were demands to increase the level of funding for traditional services, there were new demands for more individualized approaches and funding models.

People were asking serious questions about the appropriateness and responsiveness of the services available. Not all held favorable views of government social workers, who increasingly functioned as gatekeepers to a highly restrictive system. Many people felt that they didn't have much control or say in the system.

Different understandings of disability vied for attention and different understandings of the best mix of supports – formal and informal, agency-based and individually directed – competed across rural and urban communities. Services needed across the lifespan and across life situations were not well coordinated and typically lacked portability from one part of the province to the next.

Government procedures were inflexible and organized labour had come into unprecedented power and control in the system. Wage settlements achieved at the end of the previous government's regime meant service levels would have to be reduced if managers were to live within budgets.

In the balance, many families felt fearful about losing their hard won gains, alienated and even entirely shut out of the system. While change was needed, not all saw eye-to-eye on what a new set of arrangements should look like.

The Community Living Coalition

Some stakeholders in the community recognized the strategic importance of moving beyond their incidental differences of opinion and mutual mistrust towards a consensus-based approach to a new policy and program model. The new approach was to be community led and operationalized in partnership with government. They began talking in earnest with one another about a radical new initiative that would be framed as one to help government wrestle greater efficiencies from limited resources thereby reducing the growing wait lists, while at the same time affording greater flexibility, responsiveness, portability, choice, control, social inclusion and ultimately satisfaction for the users of the services provided.

Community members fashioned various proposals around those themes and ultimately came together in an unprecedented show of solidarity in the Community Living Coalition. The Coalition was able to persuade the government that the proposal it tabled enjoyed broadly based support and was the map for setting the future course of community living services in the province.

The Transition Steering Committee

The Coalition secured the resources and mandate from government to work together with government officials in a Transition Steering Committee (TSC). That committee was to develop recommendations for the Minister of MCFD on governance, resources and other arrangements that were needed to give further detail to the general map that the Coalition had developed. The TSC intended that an Interim Authority for Community Living would develop still further details, as would a fully constituted Authority for Community Living that was to operate at arm's length from government.

The TSC completed an enormous volume of work in a short space of time that required thousands of hours of volunteer effort. The scope of the TSC's work was impressive, covering topics such as community-based governance, citizenship and choice, accountability and transparency, safety and well-being and various organizational and financial implications of the proposed new system.

The latter included not only transitional funding but also the re-allocation of the present human resource complement at MCFD and other human resource implications. The TSC report also dealt with limiting the future costs to government and to the new Authority through innovation and increased productivity, and by recouping revenue through the sale of selected assets.

In its work, the TSC synthesized and refined the work that had preceded its existence, including the early pioneering efforts of the Community Living Society on individualized funding and independent planning supports and the further articulations of those ideas that occurred at various symposia and summits that were held from 1997 to 2000. The TSC synthesized within its report the "Framework Document" of the Individualized Funding Family Coalition, the "Community Governance Proposal" of the Community Living Coalition and various other documents that were generated by service providers and other groups and individuals, including the work of a provincial Joint Committee that represented diverse organizations.

While the TSC attended to matters such as draft legislation for the Interim Authority, other issues remained such as the impacts of legislation concerning employment and social assistance for people with developmental disabilities, tax implications of new financing arrangements, the transition of young people to the system of services for adults, safeguards for people currently in the community living system, inter-ministerial linkages and Treasury Board's eleventh hour determination that savings could not be carried over from one fiscal year to the next for re-investment in direct services to deal with burgeoning wait lists.

Assessment of the TSC's Work

Thirty-two individuals and organizations in BC provided written feedback on the work of the TSC. In terms of the broad directions set out in the TSC's report, the government-appointed Evaluation Committee, the British Columbia Government Employee and Service Union (BCGEU) and Family Partners were generally supportive. However, each of these groups had concerns about the lack of detail on important issues.

These included, among other things, the likely service delivery outcomes of the proposed arrangements, the actual scope and authority of the Minister of MCFD to bring about the proposed changes, implications of increased community responsibilities and service reforms in the context of government budget and service cuts, responsiveness to planning and service needs in rural communities, issues of job security and the adequacy of workers' pay, details on how to address wait lists, and community representation in any future system design and implementation arrangements. Those critiques also surfaced in the interviews conducted for the research.

Further issues were: the fast paced agenda of the TSC and of the broader system reform process; the TSC's backing of a radical new approach rather than slower-paced, incremental changes; and the need to secure and maintain broad level "buy in".

"Buy in" was compromised by the perceived insularity of the TSC and by a community outreach strategy that would ideally have been more robust, more welcoming of and responsive to community input, and that would have built on community momentum to develop a more responsive and workable system. There were the further challenges of keeping government informed and onside both during and after the TSC's work, clarifying whether families actually drove the TSC, and dealing with the issue of whether and which families would ultimately have say in decision making about eligibility and resource allocation for community living.

Technical details such as resource allocation principles and results indicators needed further work, and concerns lingered about the perceived lack of operational depth at the TSC table and the necessity of separating funding and planning functions.

The TSC's work would likely have been strengthened if greater recognition and attention had been given to the underlying values that people held in common, despite differences of opinion on practical matters. As well, the process would ideally have been structured to allow broader input and say for people who will be directly affected by system change. Questions and concerns arising from the community would have been addressed in a timely way and more progress would have been made in sorting out some challenging technical issues on resource allocation, administration of service dollars and community development. As well, stakeholders would have avoided leaving the impression that they could deliver more than was actually the case.

On a more positive note, the TSC built upon years of pioneering work by families so in that sense was driven by the contributions of families to system reforms. Although initially tense, TSC meetings and committee work became amicable and highly productive in a short period of time. If community solidarity and cohesion required further attention, the TSC served as a rallying point that contributed to a strengthening of community cohesion and an ethos of mutual assistance. The TSC helped lessen the adverse impacts of budget cuts and gave further voice to ideas that service providers used in their efforts to achieve greater efficiencies and service responsiveness. For their part, some member organizations within the Community Living Coalition managed to secure additional funding to bring people together to discuss concerns and possibilities, which in turn fed into the work of the TSC.

The leadership within the Community Living Coalition and the TSC took a pragmatic approach to "sizing up" the policy and program context and made deliberate choices to capitalize on opportunities and to respond to strategic necessities. While relationships with government could perhaps have been more diligently cultivated and maintained, the Coalition and TSC for the most part opted to work in partnership with government instead of taking an adversarial stance that was unlikely to yield positive results.

The TSC built on the vision for community living that lay at the base of its inception and developed a document that continued beyond the lifespan of the TSC to inform the work of the Interim Authority for Community Living British Columbia. A key success of the TSC's work was the creation of an Interim Authority consisting mainly of family members and self-advocates. That there continues to be a plan for a fully constituted authority for community living at arm's length from government is another significant outcome of the TSC's work.

Lessons Learned

Hindsight is twenty-twenty and there is always a risk of presenting simplistic solutions for complex problems. However, on reflection several key "lessons" do emerge from the research that could guide the future efforts to support the well being of people with developmental disabilities in BC. First, it seems reasonable that people considering any replication or continuation of the TSC process would continue doing the actions that contributed to the strengths of the process. These included: building on parent activism; furthering a positive process of collaboration and planning; financial realism and productive relationships with government. Second, if greater attention had been paid to the following considerations during and after the work of the TSC, some of the opposition and other difficulties could perhaps have been averted and allayed.

1. Building on Shared Values

A coherent set of values has emerged in the community living sector in BC that enjoys broadly based support. This can be built upon. People come and go but values remain if people are called to them. These values include, among other things:

- Dignity and respect for individuals regardless of the nature or severity of disability;
- Dignity and respect for the families of people with disabilities;
- Individualized and responsive approaches to meeting people's support requirements;
- System and program flexibility to adapt and modify supports as people's changing needs warrant;
- Portability of supports across life situations and across regions of the province;
- Substantive consumer say and control in service arrangements and in determining their own life course and solutions to the problems they face;
- Ensuring people's basic safety and well-being in the context of reasonable risk-taking and chances for a good life in the community;
- The full inclusion and participation of people with developmental and other disabilities as valued, contributing citizens in the relationships and broader social fabric of their communities; and
- Community and government responsibility to assist individuals and families to secure, in ways that are fiscally sustainable, the supports needed for inclusion and participation in society.

In the interviews and focus groups that were conducted for the research we did not hear any serious disputing of these basic values. Arguably, it makes sense for stakeholders to keep one eye trained on the underlying values that bind them together in common purpose rather than getting too embroiled in contentious discussions on practical means to ends, over which they may disagree in the near term and that can strain amicable working relations over the longer term.

2. Maintaining Bold Vision while Conserving and Extending the Present Good

Some of the difficulties could have been avoided if a workable balance had been struck between, on the one hand, audacious vision and forward-thinking and, on the other, the familiar arrangements that some people presently value because they consider the arrangements to be working reasonably well for themselves. Audacious vision and creative thinking are not necessarily at odds with the present good and incremental improvements, but unfortunately the way the change was presented, people who were presently satisfied with service arrangements felt challenged. Planning how to move forward while preserving the status quo for some individuals is clearly a challenge to be addressed.

3. Including Diverse Experiences while Upholding Principles

In a healthy democracy, the policy and program change process would ideally be structured so that the people who will be affected by its outcomes feel that they have a direct stake and say in charting the direction – that they have some ownership of the process and its results. This is important to people with disabilities and their families as, with the closures of institutions, much more focus has been given to supporting the family caregiver at home.

While the TSC clearly represented an attempt by government to involve family caregivers, it was not inclusive enough for some people. When this happens in the future, the system change process may need to be slowed down, opened up for more dialogue and collaborative problem solving, and mandated to provide for the differentiation of solutions so that these accord with local needs and preferences.

Similarly, it would have been helpful if stakeholders had found ways of being more open to the experiences, ideas and concerns of one another, even where those experiences, ideas and concerns sometimes seemed inappropriate or dissonant. Such viewpoints have to be addressed one way or another – either from within the reform process or from outside the process, demanding the attention that is due.

At the same time it will be important to safeguard over-arching principles and standards of quality to which everyone needs to be held accountable.

4. Acknowledging and Engaging Diverse Talent

While the TSC did invite input from knowledgeable experts, there was arguably a wealth of expertise within the community living sector in BC that could have been better harnessed to address various operational issues. This may have meant engaging in issue identification and solution development with a greater diversity of family members and self-advocates, or government officials and other professionals with the necessary skills and experience.

5. Addressing Questions and Concerns

It was pointed out in a few interviews that the TSC would have sent positive messages if members who didn't know the answers to questions would have been more ready to admit the fact, and would have committed to finding out and to getting back with answers or proposed solutions in a timely way.

By inference, if there were no self-evident answers or solutions, TSC members would ideally have engaged the questioners as allies in joint fact-finding, brainstorming and problem solving.

6. Doing the Needed Technical Work

Detailed technical work was needed to:

- Develop reasonably fair and fiscally sustainable approaches to resource allocation (i.e., addressing the "who gets what and on what basis" issue);

- Facilitate the “unbundling” of traditional funding and service approaches while safeguarding the well-being of people whose funding and services are not being unbundled; and to
- Develop community willingness and capacity to involve and support people with intellectual disabilities in ways that reduce their reliance on formal services while at the same time ensuring that the community continues to acknowledge and make provision for the services that will be needed.

People wrestling with such practical issues were looking for a clearer sense of how they would be addressed in the new system. The fact that the people didn’t get answers contributed to conflict that was unnecessary.

7. Setting Reasonable Limits

It would have been helpful if stakeholders – both community members and government officials – were clearer about what they could and could not realistically deliver, and about the matters on which they were uncertain. Ideally the stakeholders would have continued to work to deliver what they realistically could while avoiding the impression that was left in many people’s minds that government and community leaders were making promises that couldn’t be kept. That impression resulted in diminished confidence in the reform process and even mistrust and disillusionment. It might have been more useful to have had a regular update on issues that were currently being addressed and those that were on hold.

I. Overview

A. Introduction

On October 2, 2002, Gordon Hogg, then Minister of British Columbia's Children and Family Development (MCFD), announced that he was initiating a process that would culminate in a new Authority for Community Living Services. Responsibility for an array of services to people with developmental disabilities in British Columbia (BC) had historically fallen to the Ministry.

The *Community Services Interim Authorities Act* was passed on November 13, 2002. This move signalled the intention of Government to shift responsibility for the management of service delivery outside of government to an arm's length agency that would continue to report and be accountable to government, while reporting and being accountable in a more direct way to the users of services delivered.

This announcement came at the end of a process in which community members (i.e., family members of people with developmental disabilities, friends, advocates, self-advocates, service providers) had mobilized and articulated the need for, and their vision of, a new approach. It also brought to closure about a year of intensive work at the table of the Community Living Transition Steering Committee, which had been initiated by community members and at which they, with the support of government officials, developed an extensive outline of new arrangements. New arrangements were to be more fully articulated under the aegis of an Interim Authority, before final transition of responsibilities to the fully constituted Authority for Community Living.

B. Objectives and Scope of the Report

The present research traces the genesis of the new Authority. The objectives of the report are:

- To document the development of a new approach to community living in British Columbia, including: a) a community-based governance structure and b) a service delivery mechanism premised on inclusive and self-directed options and opportunities for persons with developmental disabilities and their families; and
- To highlight lessons learned.

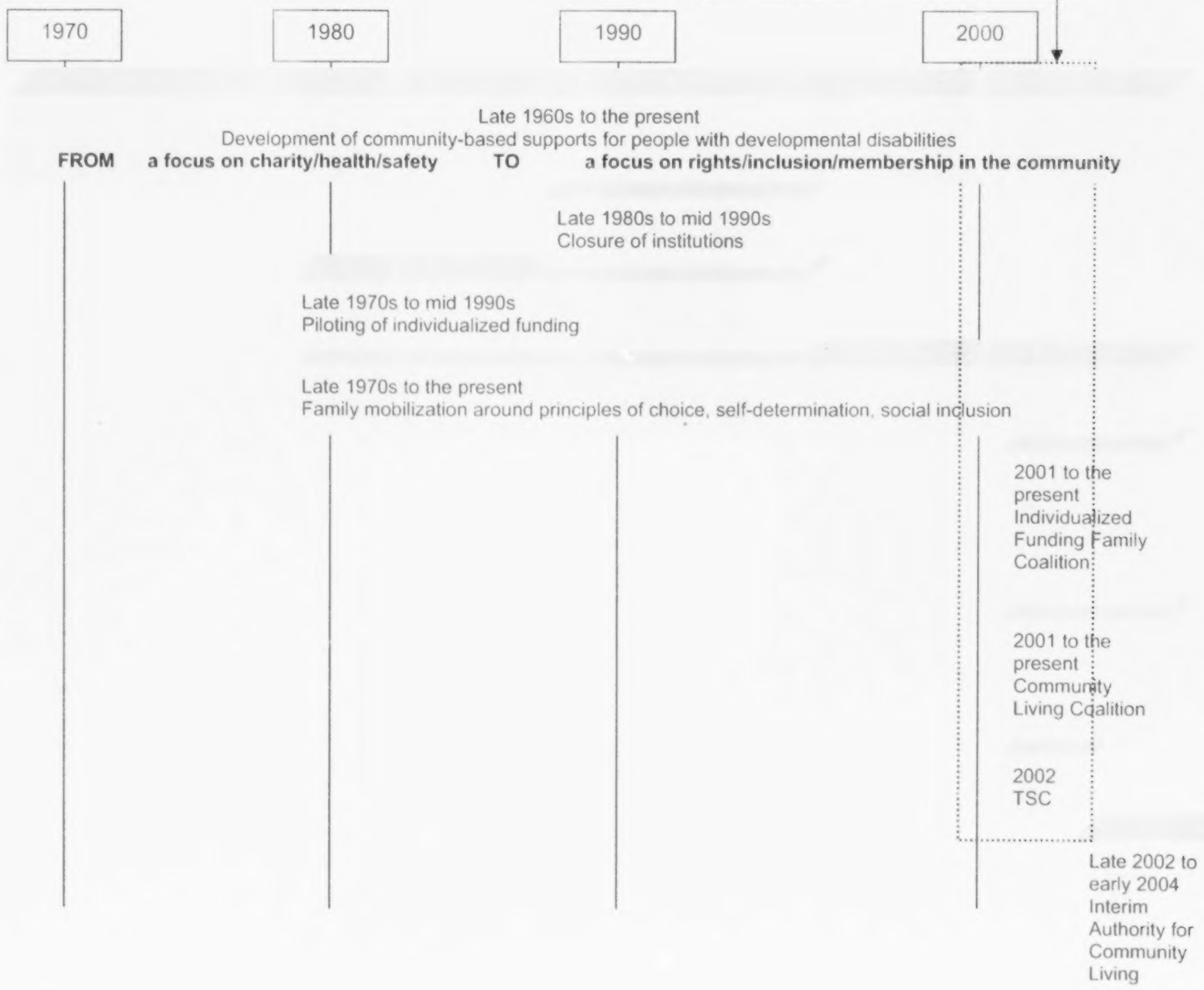
The report traces the formative factors that led to the creation of the Community Living Transition Steering Committee (TSC), which laid the basis for the work of the Interim Authority and which will no doubt continue to inform the work of any subsequent authority for community living services in BC.

As such, the present report can be considered the first phase in an evaluation process that may eventually cover the work of the Interim Authority and its successor(s). This first phase is intended to serve as a baseline for subsequent evaluative research:

First Phase of the Research		Next Phase	Next Phase
• Development of a community critique and vision for change. • Community mobilization for change.	• Proposal for and implementation of the TSC. • Completion of the TSC's work, which set the stage for an Interim Authority for Community Living. • Creation of the Interim Authority for Community Living.	• Sharing of responsibilities between the Ministry of Children and Family Development and the Interim Authority. • The work of the Interim Authority in preparing the ground for a fully constituted Authority for Community Living.	• Transition to the new Authority for Community Living. • Ongoing exercise of responsibility by the new Authority.

Figure 1 shows the time frame and coverage of the present research.

Figure 1. Time frame and coverage of most of the present research


1970
1980
1990
2000
Late 1960s to the present
Development of community-based supports for people with developmental disabilities
FROM a focus on charity/health/safety TO a focus on rights/inclusion/membership in the community
Late 1980s to mid 1990s
Closure of institutions
Late 1970s to mid 1990s
Piloting of individualized funding
Late 1970s to the present
Family mobilization around principles of choice, self-determination, social inclusion
2001 to the present Individualized Funding Family Coalition
2001 to the present Community Living Coalition
2002 TSC
Late 2002 to early 2004 Interim Authority for Community Living

C. Structure and Intended Readership of the Report

Section II of the report provides general background on the province of British Columbia and on the community living service system. Section III provides a more in-depth look at some of the difficulties and promising developments in that system. Section IV provides an overview of key initiatives by the government that helped to further define the policy and program context. Section V provides a glimpse of social developments at the community level that culminated in the formation of the Community Living Coalition, whose work is discussed in Section VI. Sections VII through IX discuss further developments in the policy context and the inception and work of the Transition Steering Committee (TSC). Section X provides a snapshot of some of the more notable critiques of the TSC's work. Section XI provides a "bare bones" discussion on the creation and mandate of the Interim Authority for Community Living, which was implemented as a result of the work of the TSC. Section XII explores some of the limitations and strengths of the TSC process and some lessons to be drawn from that process. Section XIII concludes the report.

The report is intended for the general adult reader who may not have much background in public policy, social services or disability. At the same time, it is intended for readers quite familiar with such issues and who may also be familiar with the particular situation in British Columbia.

D. Methodology

The research is based on a variety of sources of information, including key informant interviews and focus groups with people involved in, or interested in the work of, the Transition Steering Committee. In total, 47 people were interviewed or took part in the focus groups for the research.

A few interviews were conducted in April and May of 2003. Most of the interviews and focus groups took place from September through early December of that year. Cameron Crawford and Mary Anne Burke of The Roeher Institute conducted the interviews and focus groups. Cameron Crawford wrote the present report.

People interviewed and who took part in the focus groups included self-advocates, family members of people with developmental disabilities, community advocates, service providers and government officials. These people reside in large and small communities from across the province, including the Vancouver lower mainland, Vancouver Island, the interior and the north of the province.

The research also draws from minutes of various meetings, reports and briefs, correspondence and other documents available on Websites and in hard copy format.

Lines of enquiry that were pursued include the:

- need and opportunities to move from the existing system to new arrangements;
- background context of Individualized Funding;
- fiscal and policy context from the 1980s through the 1990s into the present century;
- services context;
- community and family context;
- labour context;
- political context;
- strategy story on the agenda forward for system change;
- work of the Transition Steering Committee; and the
- development and maintenance of:
    - community vision
    - community support for the transition to a new Interim Authority for Community Living
    - unity among stakeholders
    - effective communication

As well, concerns about access to resources and the equity of resource allocation were explored, as were critiques of the TSC's work.

The sheer volume of raw data to be reviewed meant that a balance had to be struck between brevity and comprehensiveness. The aim was to provide enough information so that the reader, with little or no background on British Columbia or on the factors that led up to the creation of the Interim Authority, will be able to gain a reasonably complete understanding. At the same time, an effort was made to confine the discussion to what The Roeher Institute considered to be the most salient points.

E. General Approach

A significant focus of the research is on the general background and factors that led up to the creation of the TSC. This tack was taken as a means of showing the factors with which the TSC had to grapple and the reasons for the directions of the TSC's work.

As well, regardless of the strengths and limitations of the TSC and its work, context issues that are explored in the research remain issues that The Roeher Institute believes will likely need to be addressed by any successors to the TSC, including any new Authority for Community Living, families and individuals living with a developmental disability, the broader community and government.

F. Key Concepts

Several key terms are used throughout this report. The terms "intellectual disability" and "developmental disability", while technically different, are commonly used interchangeably in British Columbia and in several other jurisdictions. The present report uses the terms interchangeably as well. The terms connote people with a significant level of intellectual difficulty (e.g., IQ < 70) and with persisting difficulty in two or more domains of everyday activity that most people undertake without significant difficulty, all of which occur before 18 years of age.

"Community living" refers to an approach to supporting people with developmental disabilities that is premised on principles of respect and human dignity, social inclusion, human rights, individualization, self-determination and individual empowerment.[1]

"Community living services" refer to the range of social services that are intended to serve people with developmental disabilities, which may or may not be grounded in the guiding principles. In British Columbia, community living services play an important role in the lives of people with intellectual disabilities and their families. These services are discussed in Sections II and III of the report.

The "community living sector" refers to the people and agencies involved in the provision of community living services or involved in advocacy and who may not be directly involved in the provision of services.

Others key concepts used in this report are explained in context.

G. External Review

A research advisory committee that was appointed by the Interim Authority's Board of Directors reviewed various drafts of this report. The advisory committee consisted of Nancy Hall, PhD (Senior Advisor, Interim Authority for Community Living British Columbia), Tim Stainton, PhD (Associate Professor, School of Social Work and Family Studies, University of British Columbia) and Lorraine Ward (Independent Accountant). Committee members provided helpful input on the overall structure of the report and on some matters of fact. The Roeher Institute is responsible for the findings of the research.

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[1] See, for instance, Canadian Association for Community Living (1985). *Community Living 2000*. Toronto: Author

II. General Background

This section of the report provides a brief look at the demographics of British Columbia, its politics in 2001, the closure of major institutions in that province over the previous two decades and the establishment of community-based options for people with intellectual disabilities. It provides a snapshot of the community living services system, the role of families in that system and government arrangements with organized labour that became problematic. It also provides an overview of broad shifts in thinking about disability in recent decades and of how those shifts have informed people's vision and expectations concerning people with disabilities.

A. British Columbia

British Columbia entered Canadian confederation in 1871 and is the westernmost of Canada's 10 provinces. As of July 2002, its population was 4.141 million people.[2]

In the provincial election of May 2001, the New Democratic Party were resoundingly defeated by the provincial Liberals. Of 79 Members of the Legislative Assembly (MLAs), 77 were Liberal and 2 were NDP.[3] The Liberals, under the leadership of Gordon Campbell, come to power on the party's *New Era* platform, with ten central commitments. Among these were commitments to: better services for children, families and First Nations; open, accountable and democratic government; and responsible, accountable management of public resources and tax dollars.[4]

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[2] Available at http://www.gov.bc.ca/bvprd/bc/category.do?action=bcFacts&categoryId=%2FNon+Ministry+or+Organization%2FProvince+Home%2FBC.+Facts&navId=NAV_ID_province

[3] Two of the Liberal members subsequently left that party to sit as independent members of the Legislative Assembly.

[4] BC Liberals (undated). *A New Era for British Columbians.*

One of the new government's earliest actions upon being sworn into public was to initiate major personal tax reductions on June 6, 2001. Business tax cuts were introduced soon afterwards on July 30.

The government also enacted a *Community Charter Council Act*.[5] The legislation was first tabled by Gordon Campbell on July 12, 1995[6] in a Private Member's Bill, which aimed to devolve responsibilities from the provincial to municipal level of government while giving increased control and autonomy to municipalities. Enacted on August of 2001, the legislation established a provincial Council to further municipal autonomy, a wider range of municipal tools to reduce reliance on property taxes and measures to prevent the provincial government from reducing its costs by transferring responsibilities to municipalities.

Thus, the new government had clearly signalled its intent to devolve some key powers and responsibilities that had historically been vested in the provincial level of government.

B. The Community Living "System"

1. From Institutions to Community Options

Prior to the 1960s, the main model of service for people with developmental disabilities in BC was institutional care. The first buildings at the Woodlands School in New Westminster were constructed in the 1870s.[7] Woodlands was the largest congregate care facility in the province for people with developmental disabilities. The Tranquille facility in Kamloops had served as a sanatorium for tuberculosis patients from 1907[8] until its conversion to a congregate care facility for people with developmental disabilities in 1958.[9] Glendale Lodge near Victoria on Vancouver Island was a newer facility built in 1976. People with developmental disabilities and psychiatric difficulties were not infrequently placed at Riverview in Port Coquitlam, a large provincial mental health facility, and in various smaller facilities. The institutional response was an outgrowth of the health services and medical models of disability.

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[5] Community Charter Community Charter Council Act [SBC 2001] Chapter 35.

[6] British Columbia, Hansard, Volume 21, Number 28, p. 16913.

[7] Dulcie McCallum (August 2001). *The Need To Know: Administrative Review of the Woodlands School.* Victoria: Ministry of Children and Family Development.

[8] BC Lung Association. Looking Back: An Association History. Available at http://www.bc.lung.ca/history.htm.

Owing in part to the influence of Normalization theory[10], institutional models came under increasing scrutiny in Canada and internationally. Pressure mounted in BC for the integration of people with developmental disabilities in the community, the fuller development of community-based services, for the closure of institutions and for the movement of people from institutions back to their communities. Beginning in the 1960s families of people with developmental disabilities had already spearheaded the creation and expansion of smaller community options (e.g., group homes, sheltered workshops) and played a lead role in lobbying for the closure of institutions.

In 1981 the Provincial Cabinet announced that the institutions of Woodlands, Glendale and Tranquille would be phased out within the following ten years, a process that began 1983. By 1985 Tranquille was closed and by 1996 the other two institutions had been closed, with the exception of Willow Clinic on the grounds of Woodlands.[11]

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[9] Wayne Norton. A Whole Little City by Itself : Tranquille and Tuberculosis, book review available at http://www.plateaupress.com/tranquille.htm.

[10] Bengt Nirje (1969). "The normalization principle and its human management implications." In R. Kugel, & W. Wolfensberger (Eds.), *Changing patterns in residential services for the mentally retarded*. Washington, D.C.: President's Committee on Mental Retardation; Wolf Wolfensberger (1970). *The principle of normalization in human services*. Toronto: National Institute on Mental Retardation.

[11] See Ministry of Social Services. *Annual Report 1995/96*, which reported that Glendale was closed in 1996 and that Woodlands was slated to be closed by December of that year.

2. Community Living Services

The present Community Living Services system grew apace of institutional closures and the growing desire of families and self advocates that people with developmental disabilities would be supported to live in their communities. In 2002 it was estimated that the Ministry for Children and Family Development was serving about 8,600 adults with developmental disabilities through a combination of staffed group homes, staffed proprietary care homes, proprietary residential family care, and semi-independent living services.[12] Others were being served through community living services such as supported employment, life skills and other skill development programs. Eligibility was based on the international standard for the definition of intellectual disability.[13]

Professional Support Services provided assessment, support, consultation, and planning to individuals or those who supported them. Professional Support Services also assisted service providers, field staff and families of adults with developmental disabilities to plan, implement, monitor and evaluate programs and services related to community living, and funded training for caregivers.

For the approximately 14,500 children and youth with special needs that received services from MCFD[14], *Infant development* provided home-based services to infants up to age three who are at risk of developmental delay or who have a developmental delay, and their families. *Supported child care* financed the extra supports children with special needs require to participate in pre-school and childcare settings. *Early Intervention* provided a network of services such as physiotherapy, occupational therapy, speech and language therapy and family support. *Behavioural Support for Children with Autism* provided special consultation, child-specific training, demonstrations of behavioural techniques, and development of behaviour management plans for children with autism and their families. The *Summer Program for the Deaf/Blind* provided individualized plans to ensure deaf/blind students maintain skills gained through the school year. *School-Aged Therapy Services* provided school-based occupational therapy and physical therapy services to school-aged children with special needs. The *Early Childhood Autism Initiative* provided intensive therapy support for children from birth to school age through three regional programs newly launched in 2001.

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[12] Les Foster, Ministry of Children & Family Development Budget & Resources (May 16, 2002). "Presentation to Community Living Services Transition Steering Group".

[13] I.e., onset of disability prior to age 18; measured significant limitations in 2 or more adaptive skill areas; and measured intellectual functioning (IQ) of approximately 70 or below.

[14] British Columbia, Ministry for Children and Families (2000). *1999/2000 Annual Report*. Victoria: Author, p. 30.

As well, there was a variety of Support Services for Families. These included the *At Home Program*, which supported families through respite and medical services who were caring for children with severe disabilities at home. *Associate Family Services* provide a trained family to work in partnership with birth parents to provide care in the trained-family home. *Nursing Support Services* provided nursing services to support at-home care. *Children and Youth Care Workers* sought to improve families' child management and/or parenting skills. *Homemaker/Home Support Workers* provided care and supervision for children, in the family home while parents were temporarily absent.[15]

In the community living services system, charities (e.g., associations for community living) and private care providers are key delivery channels, as are ministry-based services (e.g., social workers).

Non-government service providing agencies tend to be funded through block government transfers, which the agencies then use to provide services to the people they serve. Agencies may or may not earmark specific amounts for specific services for specific people. More typically, the dollars are "bundled" to meet the needs of several people in a given program (e.g., in a group home).

Following the heavy reliance on institutional care in BC, dollars once earmarked for that purpose were refocused for community-based services throughout the 1980s and 1990s as people were shifted from institutions to community options.

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[15] British Columbia, Ministry of Children and Family Development (October 2001). *Discussion Paper on Community Living Services.* Author: Victoria.

3. Informal Support – The Role of Families

Paid providers of services comprise a fraction of all personal supports to people with disabilities in the province. The most recent Participation and Activity Limitation Survey (PALS 2001) shows that only 21 per cent of adults in BC with disabilities who receive assistance with everyday activities are helped by community organizations or agencies.[16] Analysis of the Health and Activity Limitation Survey (HALS) of 1991 found that family members were generally involved in providing support to British Columbians with developmental disabilities, with agencies as the sole source of support for only 13 per cent. Statistics Canada has not yet provided provincial detail on the extent to which family members are involved in providing support to children with disabilities. However, in the vast majority of cases in Canada where the child is helped with personal care, it is family members who provide that support. A small proportion of children with disabilities receive help mostly from other sources.[17]

4. Labour and Collective Bargaining – The Munroe Agreement

The government of BC is party to a large number of contracts with service providers. In its *Annual Report* of 2001/02, MCFD estimated that it was party to 15,000 such contracts, involving 17,600 agency staff and 7,400 individuals providing family care.[18]

The *Public Sector Employers Act* (Bill 78) had been passed in 1993 to deal with coordination of human resource and labour relations policies and practices among public sector employers, and to deal with issues of communication and coordination between public sector employers and their employees. Bill 78 authorized the creation of a Public Sector Employers' Council (PSEC) and a number of employers' associations in the public sector, including the Community Social Services Employers' Association (CSSEA).

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[16] Statistics Canada (2003). *Disability Supports in Canada, 2001 – Tables.* Ottawa: Minister of Industry, Table 3.11.

[17] Statistics Canada (2003). *Children with disabilities and their families – Tables.* Ottawa: Minister of Industry, p. 7.

[18] British Columbia, Ministry of Children and Family Development (February 2002). *Ministry of Children and Family Development Service Plan 2002/2003 to 2004/2005.* Victoria. Author, p. 3.

In 2001-2002, CSSEA coordinated human resources and labour relations for member agencies that delivered social services funded by the provincial government. Its membership consisted of hundreds of social service agencies, ranging from very small to quite large organizations, both unionized and non-unionized. For unionized agencies, CSSEA functioned as the accredited bargaining agent under the BC *Labour Relations Code* and under a funding mandate established by the provincial government.

In the early 1990s, the community living sector was not as highly unionized as it became later in the decade.[19] Wages had historically been quite low – about $13.50 per hour in 1998.[20]

In 1999 there was an eleven-week strike involving 10,000 community social service workers, who were seeking parity in terms of wages and benefits with community health workers. In the collective bargaining process, unions sided against the Community Social Service Employers' Association and the government in an effort to create a provincial standard for the wages, benefits and working conditions of workers in the sector. Mediator Don Munro helped achieve a settlement that became known as the Munroe Agreement.

The agreement provided for an hourly wage of $16.83/hr for Residential Care Workers (RCW), 7.5% for equity adjustments for non-RCW's, common medical, dental, Employer Health Benefits and Long Term Disability plans, a joint benefit trust, a 3% RRSP pension plan, vacation improvements, a job security agreement with a million dollar fund, a sucessorship agreement to preserve employment and parity with community health workers.[21]

The Munroe Agreement required that wage and benefit levels be adjusted retroactively and at established future dates, with different treatment for agencies that were original parties to the Agreement as compared with agencies bargaining renewal or first collective agreements. In 2001, 260 agencies were covered by the Agreement and many more were bargaining.[22]

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[19] As of April 1, 2004 there were 108 member organizations of CSSEA in the community living services sector, comprising 6,978 full time equivalent unionized employees. See CSSEA Statistics at http://www.cssea.bc.ca/statistics.php.

[20] Community Social Services Employers' Association (March 2003). *2003 Bargaining – Getting to the Tables.* Vancouver: Author.

[21] Canadian Union of Public Employees (October 2003). *Backgrounder – Community Social Services Bargaining.* Vancouver: Author.

Towards the end of the bargaining, government and labour essentially bypassed CSSEA's Employer Bargaining Committee and dealt directly with one another. The process resulted in alienation of employers that comprised the CSSEA membership, [23] i.e., the Munroe Agreement was agreed to by unions and the government, not by employers or their bargaining agent.

For community living services, the Munroe Agreement helped to achieve wage equity and standardization of benefit packages within the unionized sector. However some service providers (and others who were interviewed or who took part in the focus groups for the present research) felt that the agreement had:

- Increased per person costs of providing services, with costs of service delivery being driven up by inflexible staffing models, unfunded administrative costs, increased responsibilities for human resources and labour relations issues.
- Reduced the ability of service providers to close programs that were not meeting needs, due to the labour costs of doing so.
- Reduced money left for wages in non-union organizations due to the large sums of money needed to address both wage and other issues in the collective agreement.
- Reduced the flexibility of service providers to deliver services on a needs basis, with worker seniority, successorship and other rights taking precedence over compatibility with, and the rights of, the individuals served.
- Limited the ability of service providers to develop new services as needed, especially for youth.

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[22] British Columbia, Ministry of Finance, Office of the Comptroller General, Internal Audit & Advisory Services (March 2002). *Report on Community Social Services Employers' Association Costing Processes - Ministry of Children and Family Development.* Victoria: Author.

[23] Community Social Services Employers' Association (March 2003). *2003 Bargaining – Getting to the Tables.* Vancouver: Author.

- Increased recruitment and retention issues due to the compression of wages between staff covered by the collective agreement, to the exclusion of management staff. [24]

The Liberal government rescinded the successorship and the promised wage increase provisions of the Munroe Agreement in January 2002.[25]

Several interview and focus group respondents spoke about the issue of successorship as particularly troubling. Essentially, under the Munroe Agreement, the "person" with a developmental disability became the "work" of the unionized employee. As the person with the disability moved, so would the employee to ensure job security. This meant that families and agencies were not at liberty to arrange for other people to provide services who may have been more suitable than those covered by the successorship provision.[26]

5. Cultural Shifts

From the late 1970s into the 21st century, broad cultural shifts were taking place within the disability sector in Canada and internationally. Community advocates had pressed for the demedicalization of services in the 1960s and 1970s. The *Canada Assistance Plan (CAP)*, a federal-provincial cost-sharing arrangement that was instituted in 1966, enabled federal sharing of provincial costs for social services, including "welfare services" to people in need or likely to be in need. This included rehabilitation, attendant service, work activity programs and various other social services to people with disabilities. Under these cost-sharing arrangements there was an increased demand by advocates for less medical approaches to disability and for a shift of some programs from under provincial ministries responsible for health to ministries responsible for social services. Service paradigms based on persons with disabilities as "clients" rather than "patients" began to take root during these years, although it must be said that such social services programs in Canada remained anchored in "residual" or welfare model. That is, they generally took the form of income tested or means tested programs for which there was no *de facto* right of entitlement, unlike health care services for which there is a *de facto* right under the principles of universality and public administration per the *Canada Health Act*, which came into effect in the 1980s.[27]

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[24] Vision for Community Living (June 2001). "Collective Bargaining". Vancouver: Author. Available at http://www.visionforcommunityliving.com/collectivebargain.htm.

[25] British Columbia (2002). Bill 29 – 2002. Health and Social Services Delivery Improvement Act.

[26] See British Columbia (2002). 2001 Legislative Session: 2nd Session, 37th Parliament, Hansard, Saturday, January 26, 2002, Morning Sitting, Volume 2, Number 2, p. 932.

The repatriation of the *Canadian Constitution* and the development of the *Canadian Charter of Rights and Freedoms* in the early 1980s saw a flurry of activity by community advocates in Canada to ensure that equality rights and freedom from discrimination would be basic constitutional entitlements irrespective of "disability" or other status. The federal *Obstacles*[28] report of the early 1980s, and the community mobilization around this parliamentary committee process, helped to build a common awareness of the difficult situation of people with disabilities in Canada.

Increasingly through the 1980s and into the late 1990s, disability advocates appealed to principles of human rights and citizenship to advance the social and economic situation of people with disabilities. Provincial human rights codes were amended to include disability as a prohibited ground for discrimination in the provincial jurisdiction. Employment equity was implemented to address the historical disadvantages that women, Aboriginal people, visible minorities and people with disabilities had experienced in federally regulated workplaces. Notions of "charity", which still inform residual programs such as welfare and social programs outside of publicly funded health and education programs in Canada, were increasingly called into question.

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[27] Monique Begin (1988). *Medicare: Canada's Right to Health*. Montreal: Optimum Publishing International.

[28] Canada, House of Commons (1981). *Obstacles: Report of the Special Committee on the Disabled and the Handicapped*. Ottawa: Minister of Supply and Services Canada.

The human rights approach to disability was mirrored internationally in various international declarations and undertakings.[29]

As an outgrowth of these developments and of the burgeoning Independent Living movement in the US and Canada, disability advocates began to use the language of empowerment and self-determination as a means of assuming greater personal control and of resisting professional control over their lives. Early Supreme Court rulings under the Charter, such as *Eve*, provided a basis of support in jurisprudence for the right to personal control over one's life, regardless of severity of disability. Principles of paternalism and state control that informed guardianship and trusteeship legislation came under increased criticism.

More recently, international disability theorists have turned their attention to the "social model" of disability, which is premised on the notion that disability is itself the disadvantage, limitations and other adverse results of interactions between impairment and the social, cultural, economic and political contexts in which people find themselves. In this model of disability, to be a "disabled person" is to be a person who has been *dis-enabled*, i.e., who has had their abilities stripped away or hampered by social and cultural circumstances.

Despite these developments, shifts in another direction were also occurring. A significant reorganization of the Ministry of Social Services occurred in 1996 following the 1995 *Report of the Gove Inquiry into Child Protection*. Responsibility for these services was vested in a new Ministry for Children and Families (subsequently the Ministry of Children and Family Development). According to several government officials and community members who took part in key informant interviews and focus groups for the present research, a "child protection" and "child welfare" orientation characterized the dominant culture of the ministry following the reorganization, and community living services took on a less important place in overall scheme of MCFD.

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[29] E.g., *Declaration of the Rights of Mentally-Retarded Persons*; *Declaration on the Rights of Disabled Persons*; World Programme of Action concerning Disabled Persons; *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*; *Sundberg Declaration on Actions and Strategies for Education, Prevention and Integration*, adopted by the UNESCO World Conference on Actions and Strategies for Education, Prevention and Integration, Malaga (Spain), 2 - 7 November 1981; *Salamanca Statement and Framework for Action on Special Needs Education*, adopted by the UNESCO World Conference on Special Needs Education: Access and Quality, Salamanca (Spain), 7 - 10 June 1994 .

The Ministry divided Community Living Services into 22 regions, each of which was to operate autonomously under a Regional Operating Officer.[30] There was also a drive to rationalize contracted services. Said one focus group participant, "This was the start of people going inward and becoming protective of their turf. It marked a shift from a service orientation to new paradigm: people would be held accountable for cost reduction." The Appendix provides more detail on the reorganization of the Ministry of Social Services.

6. Differing Visions, Expectations and Needs

Differing and sometimes dissonant visions, expectations and needs vied for attention in the community living sector. Families of an older generation, who were responsible for the creation of special education, group homes and sheltered work programs in BC, were guided by concerns about the basic safety, security and personal development of family members with developmental disabilities. Institutional placements were sometimes resorted to on this basis as well, although it must be said that before the 1970s there were few options aside from lifelong support by the family or institutional placement. This generation of families essentially created the foundations of the modern community living services system "from scratch".

Younger families have had the advantage of their children experiencing early child development programs, education, community recreation and other programs that have been informed by principles of inclusion, citizenship and human rights for the past couple of decades. Indeed, younger parents themselves developed in a cultural, political and legal context where these ideas had taken firmer root than they had for the generations coming to adulthood prior to the 1980s.

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[30] The number of regions was consolidated to 11 by the late 1990s and is presently five.

Both older and younger families have increasingly taken up the language and principles of inclusion, citizenship and human rights. However, within the community living sector quite traditional approaches to service delivery continue to be advocated, modelled much along the lines of the early pioneering efforts (e.g., group homes, other congregate care arrangements, sheltered day programs, etc).[31] These models stand alongside newer models that seek greater differentiation of program options according to individual needs and preferences, guided by principles of empowerment, choice, inclusion, human rights and so on.

As well, models of support for people with disabilities depend to some extent on the nature of the disability in question. For instance, while there are traditional and newer approaches that compete for attention and legitimacy within the community living sector, these tend not to be the same approaches that are advocated by people living primarily with mobility and agility impairments. Here, the Independent Living model has attracted widespread support and is based on assumptions of robust personal autonomy, the right to take risks and the right to develop and exercise capacity to self-manage various supports and services that may be needed for everyday living. Advocates on behalf of people with learning disabilities may prefer specialized, individualized instruction outside of the regular classroom instead of "inclusive" approaches to education advocated by people in the community living sector. Advocates on behalf of people with autism may sometimes prefer educational approaches similar to those sought by advocates for people with learning disabilities. Other modalities of support, differentiated along the lines of specific disabilities, are advocated as well.

While there are significant differences across various groups advocating on behalf of people with disabilities, underlying common values are moving in the direction of the need for personal empowerment, respectful treatment, individualized approaches to support, self-determination and choice. As well, all of the major disability groups in Canada look to publicly financed programs for a measure of support in the areas of education and learning, employment, technological support (e.g., wheelchairs, other mobility devices, technology for communication) and personal assistance (e.g., for activities of daily living, for assistance with communication such as sign language interpreters).

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[31] For instance, an article in Burnaby Now, from December 10, 2003, featured a story in which members of the Parents Support Group for Families of Mentally Handicapped Adults were advocating for the reopening of the former New Haven correction centre as a congregate facility for their adult children with developmental disabilities. The article mentioned that several of the members of the Support Group are in their eighties. Available at http://www.burnabynow.com/issues02/013102/news/013102nn2.html.

III. State of Community Living Services on the Eve of the 2001 Provincial Election

This section of the report provides an analysis of key issues in the community living services system that needed to be addressed when the TSC was mandated to carry out its work. These revolved around funding, service delivery, bureaucracy and procedures, alienation of families and the sustainability of the system. The discussion also provides an overview of some promising developments within the community living services system that the TSC could build upon.

A. Some Problems

1. Funding Issues

a. End of an Era

Several people who were interviewed for the present research characterized the 1980s and early 1990s as an "era of plenty" for the community living sector. In part the plenty was the result of funding that governments were refocusing from institutional care to the expansion of community options. As institutions closed, however, there were no further public funds to shift from institutions to the community.

The change in federal-provincial fiscal arrangements under the *Canada Health and Social Transfer* (CHST) in 1996, and the repeal of the *Canada Assistance Plan Act* and provisions, also meant a significant reduction in the cash transfers from the federal to provincial governments in Canada, resulting in a "squeeze" in all jurisdictions on social programs. In protest, British Columbia challenged the "non-residency" provision of the CHST, which was the only standard in the federal legislation aside from the continued obligation for provinces to abide by the principles of the Canada Health Act.

In the spring of 1996 the National Union of Public and General Employees (NUPGE) estimated that the reduction in transfers would total about $800 million for British Columbia, in addition to $1.7 billion lost since 1990 under the freeze on CAP and under cuts to *Established Program Financing* for health and post-secondary education services.[32] Figures from the National Council on Welfare present a less dire picture, but still a significant reduction of $457 million in federal funding for BC from 1995-96 to 1997-98.[33]

b. Growing Demands and Fiscal Pressures

Throughout the 1990s there was growing demand for community-based services, estimated by a government official interviewed for this research as ranging from 2 to 4 per cent per year.[34] Reasons given for the increase include simple population increases, in addition to the fact that people once considered to have relatively short life spans (e.g., people with Down Syndrome) are living longer, now, and may require costly interventions as they age. Service availability was not keeping pace with demand, resulting in long wait lists, a point commented upon by many people who took part in the research and confirmed by the Ministry's internal audit of adult residential services, which estimated average waits of two to four years.[35] In its response to the Audit, the Ministry commented, "The ministry recognizes that all program funds are committed which, consequentially, makes it difficult for new applicants for services to readily access community living services."[36] While those seeking services were put on wait lists, the Ministry admitted at the time that it had "no provincial formats, criteria, processes or policies … for assessing urgency and waitlist management.[37] The Office and Professional Employees International Union estimated in 2001 that 14,500 children and youth were on MCFD's wait list.[38]

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[32] National Union of Public and General Employees (NUPGE). (April 1996). *Report of the National Union's 1996 Social Services Restructuring Conference*. Available at http://www.canadiansocialresearch.net/nupgecap.htm#one%20stopbc.

[33] National Council of Welfare (1997). *Another Look at Welfare Reform*. Ottawa: Minister of Public Works and Government Services Canada, Table 1. Available at http://www.ncwcnbes.net/htmdocument/reportanolook/repanolook.htm#_britishcolumbia.

[34] See also Ministry of Children and Family Development (2002). *2001/02 Annual Report A New Era Update*, p. 29 for statistics of increasing numbers of people receiving services.

[35] Internal Audit Branch, Ministry for Children and Families (September 1997). *Internal Audit Report Residential Services Program – Persons with a Developmental Disability, Ministry for Children and Families*. Victoria: Author.

[36] Ibid., p. 10.

c. Funding Dilemmas and Priorities

The shift of MCFD to a child protection and child welfare orientation prioritized the delivery of some services at the expense of others. An internal audit of Family Support Services reported that, from the point of view of ministry regional staff,

> *"child protection cases have used more of the available services for which the ministry is gatekeeper, leaving fewer services for non-protection cases. They said that client-requested services were usually not available for non-protection cases. More recently, headquarters gave the regions direction to further reduce services for non-protection cases to relieve budget pressures. Some field staff felt this is inconsistent with ministry priorities and may lead to more child protection cases in the long term."*[39]

The Munroe Agreement brought its own dilemmas into the picture. One of the outcomes of the Agreement was a significant increase for wages in the sector. We did not detect in the interviews or focus groups for the present research any basic opposition to the principle that employees in the sector should receive adequate compensation. Indeed, one respondent related her experience with the organization in which she is involved, indicating that good compensation attracts quality employees for long-term employment and careers – people who in turn will provide quality support and advocacy for people served. However, one government official characterized the increase as "astronomical". Said another official who was interviewed, "All the money was going to meet unit costs, not to new services. So wait lists remained or got worse." The respondent indicated that the pay differential between union and non-union labour was significant, which created incentives for non-unionized workers to unionize, in turn creating further upward pressure on costs.

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[37] Ibid.

[38] opeiu 15. Available at http://www.campaignbc.com/files/page/Kit%20Sheets-Children%20and%20Families.pdf. See also BC. Council on Autism (January 15, 1998). The Crisis in Services For People with Autism in British Columbia.

[39] Internal Audit & Advisory Services, Office of the Comptroller General. Ministry of Finance (Fieldwork Completed: November 2001). *Report on Family Support Services*. Victoria: Ministry of Finance, p. 2.

Several interview respondents indicated that, as an upshot, the MCFD was essentially in a state of funding paralysis, prioritizing mainly the most serious cases involving issues of health and safety (e.g., frail elderly parents caring for middle-aged and older adult sons/daughters; families facing imminent break down). A government official reported that such approvals, which had historically been made in Victoria, were shifted to the field. However, "The regional managers had no real authority because there was no money to spend," and even health and safety spending was adding to the deficit.

The labour rates that had been negotiated also meant that the allocated budget could not continue to fund same level of services – not, at least, services based on a continuation of past practices and models. The conundrum – for government and for community agencies – lay in how to honour the Munroe Agreement without reducing service levels.[40] Respondents in one focus group indicated that several agencies began to reduce services beginning in 2000-01, which contributed to service restrictions, lack of availability and long wait lists. Said one respondent, who echoed the view of several others who were interviewed, "Employers didn't sign off [on the Agreement] but had to find the money to meet the terms and conditions."

As well, the tensions that exist in virtually all systems between funding for administration/central operations and funding for direct services were an issue. Some commented on the significant increase of funding for MCFD administrative functions after the reorganization of that Ministry, which was not matched by a corresponding increase in funding for direct services.[41]

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[40] The government subsequently rescinded the Munroe Settlement, which left unionized labour feeling betrayed in the process.

[41] The Office for the Comptroller General made the point that little funding was available under family support services for issues aside from child protection. See British Columbia, Ministry of Finance, Office of the Comptroller General, Internal Audit & Advisory Services (November 2001). *Report on Family Support Services - Ministry of Children and Family Development*. Victoria: Author, p. 2 and 9. Of total expenditures of $1.35 billion in fiscal 1999/2000, only $25.6 million was spent on Special Needs Family Support, or 1.9 per cent. See British Columbia, Ministry of Children and Families (2000). *1999/2000 Annual Report*. Victoria: Author, p. 8.

d. Efficiencies and Cost

In its *Annual Report* for 2001/02, MCFD reported per person costs of $59,000 on average for the 8,657 adults in the community living services system at the time.[42] The numbers of people receiving services had risen steadily since 1997. As the average was based on total costs for adult community living services divided by the total number of open files (i.e., people receiving residential services or day programs),[43] the average per person cost of residential services would have been even higher.[44] The *Annual Report* said, "A reduction in the average cost per client is essential to ensuring the sustainability of the new system".[45]

In its *Service Plan* for 2002/03 - 2004/05, the Ministry was targeting a 20 per cent cost reduction per person.[46] In addition to facing increasing numbers of people, the Ministry was serving an increased proportion of people with "high needs" and wages continued to comprise the largest cost component,[47] although, as one interview respondent pointed out, realty values and mortgages for group homes in some communities, e.g., near Woodlands and Glendale, were also high, which contributed to the escalating cost problem.

Such figures called into question the efficiency of traditional service delivery models. The issue of cost and efficiency had already led the Ministry to conduct an internal audit of service utilization patterns in the sector in 1997.[48] A proposal by a group of advocates in 1999 pointed to service cost as a key problem.[49] A discussion paper developed shortly after the provincial election by Vision for Community Living, a group of community living service providers in BC, stated that the Munroe agreement, while contributing to career-level wages, wage equity and standardization of benefits in the sector, had significantly increased per person costs and had hampered what some service providers believed could be more cost-effective modes of service provision.[50]

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[42] Ministry of Children and Family Development (2002). *2001/02 Annual Report A New Era Update.* Victoria: Author. pp. 29 - 30.

[43] *Ibid.*, p. 12 and 29.

[44] The Roeher Institute was informed that people receiving residential services make up about half of all people receiving adult community living services in BC. Residential services are generally more labour intensive than day programs.

[45] *Ibid.*, p. 29.

[46] Ministry of Children and Family Development (February 2002). *2002/2003 – 2004/2005 Service Plan.* Victoria: Author. p. 8. There is a gap between the estimated costs and numbers of people served as reported in this document and in the 2001/2002 annual report. The Annual Report explains the difference on p. 29..

[47] Internal Audit Branch, Ministry for Children and Families (September 1997). *Internal Audit Report Residential Services Program – Persons with a Developmental Disability, Ministry for Children and Families.* Victoria: Author.

[48] Ibid., p. 29.

Costs also had an impact on families. Said one respondent reflecting on his family's situation in 2001-2002, "If you had a child in your home, you had to bring in a unionized person.... I couldn't pay $8 per hour for respite. I had to pay $17 to $18 per hour. I couldn't afford it." Several other interview respondents spoke about costs that were falling to families as well.

e. Funding Equity and Access

In addition to spiralling overall and per person costs, the issue of equity loomed. Some people were receiving services while others were not, some received more and some received less, even though needs were similar.

The issue of equity played out geographically. One person who was interviewed for the research said, "On the mainland, a person could get $100, but the impression was created in rural communities that only $50 was available. Families didn't know any better." A submission by the Central Okanagan Community Living Services for Children Team to the provincial Core Services Review (discussed later in this report) noted the regional inequities in funding, amounting to differences of up to $50,000 per child per year. The team commented, "That great a discrepancy is not justifiable."

Even within a given system in the same region there were inequities. Said an internal audit team of residential services for children with high needs:

> *In many regions there are group homes with similar programs, but substantially different funding, which indicates that some contractors are*

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[49] Advocates and Families from South Fraser, North Shore & Capital Regions (November 19, 1998). "Proposal to Implement Individualized Funding for People with Disabilities."

[50] Vision for Community Living (June 2001). *Collective Bargaining Discussion Paper.* Available at http://www.visionforcommunityliving.com/collectivebargain.htm.

> *providing services more economically than others. For example, we noted in one region a contract for a five bed group home was $7,250 per month plus $420 per month per child. Another five bed group home contract in the same region, for similar age and problem children, was $28,700 per month plus $395 per month per child. At full capacity, these contracts work out to $112,200 and $368,100 respectively, for apparently similar services. While our examples are simplistic, they illustrate that the ministry and regions need to perform financial reviews and program monitoring to determine if the rates are justified.*[51]

Similarly, a document prepared by MCFD Community Living in the South Fraser region showed the significant differences in funding attached to group home "beds" by various service arrangements (e.g., non-profit agencies, proprietary care, family care) for similar types of service.[52]

Several interview respondents spoke about the frustration of families in their efforts to get *any* support at all, which was especially galling in that, in the words of one person, foster care providers "get virtually anything they ask for".[53]

Other interview respondents directly related their own, or commented about other families', fears and concerns about losing the hard won access and resources they had managed to secure.

Issues of equity and adequacy also played out across age lines. Interview respondents and documentation[54] referred to the lack of supports for children upon turning 19 years of age. In effect, these young people move from the system for children to that for adults, which was already waitlisted for several years. One respondent, echoing the views of several others who were interviewed, said that there were essentially no supports, leaving young adults completely dependent of family members for care and for something to do during the day – a "Very serious situation that impacts the whole family," he said.

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[51] Internal Audit Branch, Ministry for Children and Families (October 1997). *Internal Audit Report, Residential Programs, Children in Care.* Victoria: Ministry of Children and Families, pp. 24-25.

[52] MCFD --South Fraser Region, CLS - Contracts and Resources Team (October 21, 2001). Submission: Core Services Review.

[53] Terry Keough (November 2001). Letter submitted to Core Services Review.

[54] Coalition for Community Service Provision for People with Disabilities (November 1995). "'Hitting The Wall' - A Brief"; B.C. Council on Autism (January 15, 1998). "The Crisis in Services For People with Autism in British Columbia - A Brief by the B.C. Council on Autism". Vancouver: Author.

As well, in order to qualify for adult services, a person must be found to have an IQ less than 70 and have difficulty with two or more activities of everyday living, whereas this criterion did not apply for children with special needs. So, for instance, a child with autism who qualified for children's services and whose IQ was greater than 70 would not qualify for community living services at nineteen years of age, although their needs for support would persist into adulthood.

f. Competing Funding Models

Also in the mix were divergent views of the most appropriate funding models. On one level, there was widespread agreement – in the interviews we conducted and in documentation we consulted – that individualized approaches were needed for responding to the needs of people in the community living services system. There was also widespread agreement *in principle* that Individualized Funding should be available as an option for individuals and families who wanted this. Individualized Funding is discussed in further detail, below.

However, some saw Individualized Funding as a "red herring" that was immaterial as long as individualized approaches to responding to people's needs were in place in block-funded agencies.

What, then, was relationship between Individualized and traditional block funding? What was the ideal mix? How were these two funding approaches to be operationalized? For several interview respondents, the answers to these questions were not self-evident.

2. Service Issues

a. Appropriateness and Responsiveness

The appropriateness of community living services available to people who were able to secure services was an issue for some people. For example, one interview respondent related how some people were taking *any* services that were available, even if they didn't really meet needs.

An internal audit conducted for MCFD found situations where people who were quite capable of greater independence were living in a staffed residence that had been intended for people with "high needs". The auditors suggested that these people would be better served in a support model that accorded greater independence.[55]

A "shop floor" approach had also crept into the system in which people's homes were treated as unionized workplaces in some instances. A group of service providers characterized this situation as "philosophically and practically unacceptable". [56] In the view of Community Living social workers in the South Fraser Region, union successorship had resulted in the rights of labour having disproportionate weight in the balance with consumers. The social workers argued that client rights should be accorded "override" if other service providers were more beneficial to clients and more cost effective.[57]

Given the overall "child protection" approach of MCFD, several respondents commented how families felt scrutinized instead of being respectfully listened to by social workers, who had been trained and conditioned to err on the side of the safety of children. Groups with such diverse interests such as the Burnaby Association for Community Living and the Families for Early Autism Treatment of British Columbia (FEAT) had basic problems with this orientation. The ACL wrote in one of its briefs that families were tired as being seen as "dysfunctional" through the child welfare lens.[58] FEAT objected to means testing and the model of "social services distress" that was grounded in a welfare approach.[59] The latter organization also took issue with the negative characterization of families under the MCFD lens.[60]

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[55] Ministry for Children and Families, Internal Audit Branch (September 1997). *Internal Audit Report Residential Services Program – Persons with a Developmental Disability*. Victoria: Author.

[56] Vision for Community Living (July 17, 2001). MCFD Deregulation Meeting with BCACL Executive Directors. Available at http://www.visionforcommunityliving.com/deregulation0701.htm.

[57] "A Group Of Adult Community Living Services Social Workers South Fraser Region". November 8 (2001). "Submission: Core Services Review".

[58] Carol Stinson, Burnaby Association for the Mentally Handicapped (November 2, 2001). Letter to Minister Hogg.

[59] Families for Early Autism Treatment of British Columbia (August 2001). "Choices in Autism Treatment ('CIAT') – Implementing parental choice in autism health care". Vancouver: Author.

According to another respondent, arrangements for the purchase of services outside the traditional system resulted not only in the diversion of funding and increased operating costs for remaining services, but an outflow from the system of talent and capacity for service effectiveness.

b. Ambivalent Views of the Role of MCFD Social Workers

In the interviews, we found that perceptions of the role and value of MCFD social workers spanned extremes. Some interview respondents found social workers to be knowledgeable and helpful. Others saw social workers as intrusive gatekeepers to be gotten *over* or *around* rather than as people to be worked *with*. Some wanted to retain social workers in the system, while others wanted them to be disbanded entirely, disbanded largely or shifted to other administrative structures (e.g., attached to the direct services system).

c. Issues of Control

Issues concerning control were in play on several fronts as well. Said one respondent, “You couldn't *'dot an i'* without getting their [the Ministry's] okay. It was getting worse throughout 90's. More control, less money.” A service provider said that, “The Ministry and licensing were very controlling to the detriment of quality services.” Licensing requirements for residential arrangements reportedly continued to increase through the 1990s, and the Regulations became, in the words of one respondent, “more draconian”.

A parent said, “People felt slotted into empty spots or programs. Lots of families were very unhappy. They wanted more flex and control over services.” Another said, “For kids moving through inclusive educational system, families wanted more say and control and not sheltered placements.” Another parent related how a “phenomenal” support worker had been prevented from supporting her son in the educational system because it meant taking away a unionized person's job. She characterized this arrangement as a "huge waste of potential".

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[60] E.g., that families were presumed to be deficient, at the 'low end' of the socio-economic spectrum, poorly educated and 'like 'all the rest' of the social services recipients… not responsible enough to be trusted with the money.” Ibid., p. 9.

d. Competing Social and Health Models

While from the 1970s through 1990s there was generally a shift in thinking away from the medical model towards a social understanding of disability and the social model of support and service to people with disabilities, this was not a universal shift. Some groups, such as Families for Early Autism Treatment (FEAT) of British Columbia, were arguing that autism is essentially a medical condition and that people with this condition ought to be accorded the same access to service as people with any other medical condition, i.e., that access should not be dependent on means testing and that the services should be fully cost-covered under the provincial Medical Services Plan. FEAT had basic problems with the competency of MCFD to administer delivery of services to people with autism spectrum disorder, took issue with the kinds of services that the Ministry prioritized, and felt that service arrangements were inefficient and wasteful. The group argued instead that the Ministry of Health (MOH) was better suited to the administrative functions, more likely to deliver the services that people with autism needed, that physicians were more inclined to prescribe such services than were MCFD social workers, and that arrangements under MOH were likely to be more cost-efficient.[61]

Similarly, the Autism Society of BC (ASBC) agreed with a recent court decision[62] that autism is essentially a medical condition that could improve significantly with appropriate treatment. However, ASBC argued that the need for treatment does not end in the pre-school years and that the medical system needed to move away from a traditional model "to include traditionally non-medical expertise" (i.e., behavioural treatment services) across the lifespan.[63]

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[61] Families for Early Autism Treatment of British Columbia (August 2001). "Choices in Autism Treatment ('CIAT') – Implementing parental choice in autism health care". Vancouver: Author.

[62] In *Auton vs. Attorney General of BC*, BC Supreme Court Madame Justice Allan ruled that the provincial government was constitutionally obligated to fund medically necessary intervention services for children diagnosed with autism and Autism Spectrum Disorder (ASD). The court acknowledged that no one therapy is appropriate for all children affected with ASD and stopped short of ordering the province to fund Lovaas therapy specifically and of ordering the Medical Services Commission (MSC) to list Lovaas behavioural therapists as service providers. See British Columbia, Ministry of Children and Family Development (May 2003). *Factsheet – Auton vs. Attorney General of BC, et al.* Victoria: Author.

e. Competing Cultures

Several interview respondents drew attention to the formal-informal mix of services and supports that are often different in rural and smaller compared with larger urban communities. Respondents indicated that there tends to be more flexibility to organize supports in ways that work for people in smaller communities, a point not always appreciated in larger centres.

Analysis of the Health and Activity Limitation Survey (HALS) of 1991 for BC found that people with disabilities living in urban communities outside of Vancouver were actually proportionately *more* likely to be receiving community services from organizations/agencies to assist with activities of everyday living (54% compared with 15%, respectively, among those needing such support) and less reliant on family and friends as the sole source of support (39% compared with 69%, respectively). The population counts for people with developmental disabilities are too low for general release, but reflect the same general pattern. The percentage of people with disabilities needing help with everyday activities and getting no support at all was also higher in Vancouver (15% compared with 7% in other urban communities).

These observations and findings help to explain why some people who were interviewed did not see the need for a major overhaul of service arrangements in smaller urban communities and why the appeal for new arrangements emerged strongest in the Vancouver Lower Mainland area.

f. Professionalism vs. Community and Informal Support

While families continued to play a major role in the overall "system" of community living supports across the province, the view took hold that growing problems were in part a result of heavy reliance on services instead of on less professionalized and more innovative options.[64] The opinion may have been a more accurate characterization of the situation on the Lower Mainland than of communities outside of Vancouver.

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[63] Autism Society of British Columbia (April 12, 2001). *An Autism Care Pathway: The Need for 'Cradle to Grave' Treatment of Children and Adults with Autism Spectrum Disorders – A Brief by the ASBC Board of Directors.* Vancouver: Author, p. 4.

g. Management and Coordination of Supports Across the Lifespan

The inequities in funding for school-aged children compared with older youth indicated difficulties in the management and coordination of services across the lifespan. It was not a smooth journey for young adults making the transition from the children's service system (i.e., the educational system and the community living services system for children) to the community living services system for adults.

h. Management and Coordination of Supports Across the For-Profit and Voluntary Sectors

There were also issues concerning the ability of the Ministry to manage private service operators in the absence of an intermediary body analogous to the provincial Association for Community Living. Lack of such an intermediary left pressures in place for the Ministry to retain a cadre of social workers. According to a government official who was interviewed, ministry social workers were less necessary as an interface with the ACL network because that network had its own internal coordinative capacity.

As well, there was a lack of coordination between services provided under MCFD and those provided under Education, Health and Human Resources (e.g., social assistance / Disability Benefits).

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[64] British Columbia, Ministry of Children and Family Development (October 2001). *Discussion Paper on Community Living Services*. Victoria: Author, p. 5.

i. Service Portability and Administration Arrangements

Several respondents spoke about the lack of portability of services from one part of the province to the next. That issue was also evident in documentation that was reviewed.

The issue of portability in turn fed into people's conceptions of whether a more centralized or less centralized community living services system was needed. An advantage of a decentralized system with major responsibilities vested at the regional or local level is that there is the potential for decisions about resource allocation to be framed with a clear view to individual people whose profiles, needs and aspirations are known and understood at the local level. A drawback of decentralization is that it can result in a series of sub-systems with little consistency from place to place and little chance of people moving their supports – and therefore costs – from one decision-making authority to the next across the province. In effect, people receiving support can become hostages to their locale. An advantage of a centralized system is that there can be greater consistency in decision-making and greater possibility of moving supports and costs from one region to the next, because administrative and funding responsibility ultimately falls to one decision-making authority. A disadvantage is that decisions made at the "centre" or "top" may be based on only a cursory understanding of the people for whom supports and funding have been requested. Supports may be more portable, but less adequate in the balance.

3. Inflexible Bureaucracy and Procedures

Many people who were interviewed commented on the rigidity and inflexibility of the community living services system. Thirty-six submissions to the Core Services Review (discussed later) touched on the need for system flexibility and five critiqued the rigidity and inflexibility of eligibility and other administrative arrangements. An Audit of Family Support Services found the following:

> *"Too often clients must be fit into the services the contractors provide, rather than the services being shaped to fit clients' needs.*
>
> > *• Some contractors have been reluctant to modify their services for various reasons.*
> >
> > *• Even when contractors are willing to comply with requests for service modification, the contractors often find it difficult due to collective agreements, the Munroe Agreement and the related accords. Similarly, terminating contracts for services that have become relatively ineffective is also difficult. It has also become very expensive for a contractor to lay off staff whose skills are redundant, and retraining such people can be impractical and challenging. As a result, the regions' effectiveness is compromised to the extent that they are living with contracts with which they are not satisfied."*[65]

Interview respondents echoed those concerns about the difficulty of organizing services to meet needs (e.g., inability to secure a week or so of consecutive respite days instead of two weekends per month; inability to secure in-home rather than out-of-home respite support; difficulties securing after-school support for children, or after-day program support for adults whose parents were working).

Also mentioned were rules that required minimum shifts of – and pay for – four hours of labour when this many hours may not be needed. The reduction in hourly pay for more than a fixed number of hours of labour per day was problematic[66] as was having to pay money for unionized staff when non-unionized persons were perceived as better suited to individual and family needs. Employment Standards, Residential Care Facilities regulations and a range of other difficulties had to be managed as well.

Said one person who was interviewed, "a parent wanted respite for a weekend per month. The parent wanted some time away on that weekend. The government said, 'No, but we can give 8 hours per day, five days a week.' Parents would take the money and overpay for weekend support. Everyone loses – the government pays more and others who need respite don't get any." Said another respondent, "The system has often driven families' lives. The system's bureaucracy is inflexible. Individuals and families have to jump through hoops that make no sense. [Once children have reached nineteen years of age, families] have to re-engage and start over for adult people."

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[65] British Columbia, Ministry of Finance, Office of the Comptroller General, Internal Audit & Advisory Services (November 2001). *Report on Family Support Services – Ministry of Children and Family Development.* Victoria: Author. pp. 33-34.

[66] This reportedly created disincentives for service providers to provide service beyond the point at which the lower pay scale came into effect. Said one respondent, "There was no incentive [for a service provider] to take one child for the whole day. It was better to line up three kids at eight hours each. There was no real respite for parents in this arrangement."

While such comments were common in the interviews, they were not universal. Said one social worker from a rural area, "Contractors and agencies are doing lots of innovation and cost-effective support, but this is not generally recognized at the [MCFD] management level… One way or another social workers have made things work. They have the ability to get around and be close to service providers and families. They drop in and ask contractors what they need. Where evening supports and weekend supports were needed, they found ways of doing this… There's a robust ability among service providers and social workers to get together and figure out how to make things work." Said a parent who commented on government Community Living managers who were responsible for communities in which they did not live, "they didn't see what was actually happening. Just numbers and paper. They never saw how people were coming together to make things work."

While management within government may not have widely appreciated these efforts, it is probably fair to say that community advocates did not have a widespread appreciation of the efforts, either.

4. Alienation of Families

In speaking with family members who took part in the research, many expressed a sense of alienation from government and from the community living system. Speaking of older families one respondent said, "At time of deinstutionalization, the government promised families that they should 'hang in' and that, once institutions were closed, the government would be there for them. The government would help to develop residential options for family members who were aging. The government changed and the resources weren't available. Promises to families were broken. People were not just exasperated but angry." Younger family members who wanted more individualized, flexible support expressed frustration and alienation over not being able to "get in system" in the first place, and, if in the system, over not having access to the kinds and adequacy of services sought.

5. Sustainability Crisis

The system, then, was facing a sustainability crisis[67] in terms of the adequacy of its funding, its capacity to meet ever-growing demand for community living services and its qualitative responsiveness to needs. At play were internally contradictory philosophical bases and orientations, the competing understandings of disability that the system had to manage, rigid administrative rules and procedures, limited capacity to coordinate services within and beyond the MDFD and ACL framework, the lack of perceived fairness, and the system's perceived lack of supportiveness and trustworthiness to individuals and families.

B. Some Promising Developments

1. At Home Program

Despite the shortcomings of the community living system, positive things had been happening. In the interviews conducted for this research, several respondents spoke favourably about the At Home Program, although pointed out that the program has been harder to access of late and is only available for children 18 years and younger.

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[67] The general problem was recognized by the previous government. See, for instance, British Columbia, Ministry for Children and Families (2000). *Resource Management Strategy for Community Living Service Delivery.* Victoria: Author.

The At Home Program was designed in consultation with families in the 1980s and assists parents with some of the extraordinary costs of caring for a child with severe disabilities at home.

Eligible families may choose *respite services* that suit their needs. Parents are responsible for arranging for respite care, paying caregivers, managing their respite budget, and providing a record of respite expenditures. Funding can take the form of a monthly payment or reimbursement for expenses up to capped limits. The system retains discretion to fund people at different levels for respite.

Medical Benefits includes dental/orthodontic and optical benefits, hearing aids, a range of "medical" equipment (including mobility devices and braces), provincial Medical Services Plan coverage, medical supplies, incontinence supplies, medical transportation, medications and Pharmacare, and school-aged extended therapies. The latter include physiotherapy, occupational therapy, speech language pathology, chiropractic and massage services for school-aged children if the therapies are not available through existing programs (e.g., such as therapies available through the provincial health care system or the school districts).[68]

One parent who was interviewed commented on how she could make quite flexible support arrangements under the program. Another indicated that the program helped her recognize that she had capacity to manage supports, to define what was relevant to her son and family, and to put those supports in place. The program left her with positive experience of flexibility and support to meet individual needs, and a sense of family capability. There were several other favourable comments about this program as well, and the government held it out as an initiative about which it was particularly proud.[69]

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[68] The services must be pre-approved, delivered by a qualified professional and are provided to a maximum of 24 hours during a six month period.

[69] British Columbia, Ministry of Children and Family Development (October 2001). *Discussion Paper on Community Living Services.* Victoria: Author. p. 11.

2. Innovations in the Community Services System

Some service providers had been moving their approaches to service provision into line with the emerging culture and expectations of consumer empowerment, self-determination, rights and individualization of support. One interview respondent spoke favourably about the provincial service accreditation process[70] that his organization underwent in furthering these aims. The respondent referred to how the process was "entirely focused on the consumer" [i.e., the person with a disability], yielding "astonishing results in staff… summed up in one word, *respect*." A government official who was interviewed commented on the "great strides in meeting quality standards improvements" through the accreditation process, stating further that "community living agencies have led the way on this." Some, however, were less sanguine about the provincial accreditation process.[71]

Several interview respondents spoke positively about collaborative approaches to service provision, especially in smaller communities, that involved families, service providers and government officials/MCFD social workers in common efforts to make the best of limited financial and other resources.

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[70] Accreditation involves a formal process of organizational development and review, focusing on service quality, accountability, and overall organizational competence. It identifies that an agency has met organizational and program/service standards developed by consumers, stakeholders, professionals and provincial and national organizations. Currently in BC., agencies in the Aboriginal, community living and children's sectors must apply for accreditation with if they receive $500,000 or more from the Ministry. The policy was introduced in July 1999, at which time the funding threshold was $350,000.

One of the accrediting bodies that MCFD recognizes is Commission on Accreditation of Rehabilitation Facilities (CARF). The other is The Council on Accreditation for Children and Family Services (COA).

Principles inherent in the accreditation process include promotion of human rights, involvement of the person served (e.g., in planning services), design of services to enhance self-sufficiency and quality of life, and individualized, goal-oriented team approach leading to desired outcomes.

Accreditation normally requires that an organisation have numerous management controls in place related to how resources are used. Accordingly, accreditation may serve as a proxy measure of "value for money" and efficient use of available resources in providing services. Links are available at http://www.mcf.gov.bc.ca/accreditation/index.htm

[71] One organization's submission for the Core Services Review critiqued the "…imported accreditation system that does not reflect the vision of British Columbia's community living sector.". See Provincial Monitoring Group (October 31, 2001). *A View to Effective and Efficient Quality Assurance in British Columbia Submitted by the Provincial Monitoring Group.* Vancouver(?): Author. p. 3.

Other respondents spoke favourably about significant changes that had taken place in people's lives as result of not being in institutions. One commented about simple things, like "people having their own clothes, being able to get a drink from the fridge when they want" and other freedoms and opportunities that all contributed to personal development. "People who were non-verbal were beginning to communicate", she said.[72] "There was a gradual shift in the role of support staff, who began to ask questions like, 'Whose home is this? Whose service?' " There was growing recognition that the home was that of the people served, not that of staff.

As well, there was a shift in the kinds of services and interventions needed and provided, with reportedly much less in the way of behavioural orientation than previously and a shift from site-based work and other day program projects to community access (e.g., recreation, supported volunteerism). Some of the impacts were that, in the words of one person who was interviewed, "staff began to see people from a *contribution* perspective instead of *needing-taking* point of view. People began to develop relationships, for example at the fitness class. People began to go to the coffee shop of their choice and interacting with regulars. Support staffs' attitudes began to change."

Families and service providers also began to see in the 1980s and 1990s that supported employment could help foster a good life for people.

3. Support Networks, Circles of Friends

There was growing recognition in BC that people can be vulnerable if not embedded in the social fabric of their community. Beginning in the late 1980s, the spotlight had been placed on issues of sexual and other abuses against people with disabilities in Canada.[73] With the movement of people from institutions to the community, it became clear early on in the process that some individuals lacked family members to provide informal support and advocacy

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[72] See also the Blind Deaf Rubella Housing Society (November 20, 2001). Letter to Honourable Gordon Hogg. (Submitted for Core Services Review.)

[73] E.g., The Roeher Institute (1988). *Vulnerable: Sexual Abuse and People with an Intellectual Handicap*. Toronto: Author.

(e.g., because family members had died, had moved or because the family unit had disintegrated). Nor did they have friends in the community, yet. Accordingly, there were efforts to create personal support networks, "Circles of Friends" and other measures to embed people in socially valuing relationships in the community.[74]

In the 1990s, some families and service providers were continuing their work to foster better connections/ relationships between people with disabilities and others in the community. They had moved away from the view that funding and services are the only things needed, and saw the need for community development resources to innovate in this area.

4. Microboards

People also had positive experiences with "microboards", if not necessarily uniformly so. The Services to the Handicapped branch of the Ministry of Health was created in the 1980s to deal with the move of people from Tranquille to the community. Microboards were devised to arrange supports for these people on an individualized basis.

A microboard is a "small group of committed family and/or friends who join with a person to create a non-profit society that addresses the person's needs in an empowering and customized fashion and administers funds allocated to the person for supports and services."[75] Services can be purchased from agencies or privately from individuals.

Some people who were interviewed saw microboards as mechanisms for according legal status to funding arrangements for people with developmental disabilities who would typically not be considered capable under law of entering into legal contracts.[76] Others spoke about microboards as tools for social support and advocacy. Microboards lend themselves to both functions. The initial successes with microboards "snowballed"; there are presently about 170 in BC.

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[74] See, for instance, Robert Perske (1998). *Circles of Friends*. Abingdon Press; The Roeher Institute (1990). *Making Friends: Developing Relationships between People with a Disability and Other Members of the Community*. North York: Author. More recently, see Al Etmanski (2000). A *Good Life: for you and your relative with a disability*. Burnaby: Planned Lifetime Advocacy Network (PLAN).

[75] http://www.bcacl.org/policy/funding.shtml

When the ministry reorganized in 1996, a few people who had seen the benefits of microboards pushed to have them preserved as a template for future support arrangements. Said one respondent, "A huge chunk of people younger than twenty do not identify with agency care and ACL [Association for Community Living] services at all. They want an alternative. They want input and say. Agencies recognize that they won't get these kids unless they do business differently. So there has been a spike in demand for microboards." Several others spoke about how they looked for some kind of arrangements to carry on their generally positive experiences under the At Home Program once their children were no longer eligible for that program. "Other available options were so foreign to what families envisioned", commented one respondent on why there was interest in microboards.

While we heard favourable reports about microboards, we also heard from parents and others that they require a level of time, energy and involvement that family members may find difficult to sustain – especially parents who are exhausted from years of advocating with educators, social workers and doctors. Commented one respondent, "some of these parents are saying that in a few years we will be too old to keep doing this [i.e., maintain their involvement in microboards]. Parents are built into supports. They do 'shifts' during the week, do volunteer hiring, firing, accounting for funding. They don't want to be doing this forever." Another respondent, a parent, considered the microboard idea "too time consuming" but considered the prospect of having direct access to funding "quite exciting".

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[76] A minimum of five people must be on the Microboard to satisfy legal requirements of the *Society Act* in BC. The person for whom a board is established may sit on their own Microboard and can be counted as one of the five members (See http://www.microboard.org/whatis.html#1.) A registered Society can qualify as the legal entity responsible for managing transfers of provincial funding for the purchase of social services.

5. Individualized Funding

Some of the promising developments in the community living sector were in part the result of Individualized Funding. As defined on the Website for the British Columbia Association for Community Living, Individualized Funding "is a method of delivering services by providing funds directly to individuals or their families, so that they can purchase individualized services that support their own vision of how they want to live and how they want to participate in their community."[77]

Individualized Funding stands in contrast to traditional approaches to the funding of social services, which consist of block transfers of public funds to third party agencies (e.g., charities, non-profit societies, for-profit service providers) to address the needs of a range of agency "clients". Under traditional arrangements, agencies funded by government typically determine or assist in the determination of eligibility for agency services, hold primary decision-making authority about the objectives for which the funding is to be used and retain key responsibilities for organizing the specific service arrangements for meeting those objectives. There may be little in the way of direct relationship between funds allocated to the agency and specific outcomes to be achieved in the life of a client, other than that his or her basic health and safety would be safeguarded.[78]

Under individualized approaches, individuals (or their personal networks) are deemed eligible for funding by government. While accountable to government for the use of public funds, individuals who are funded (and their families/networks) hold primary decision-making authority for determining the objectives to be met (e.g., personal living goals) and the ways and means of using the funding to achieve those objectives (e.g., the agencies or individual people to be hired, technologies to be utilized and other supports to assist in realizing the goals).

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[77] http://www.bcacl.org/issues/funding/index.shtml

[78] The provincial Accreditation process might be viewed as an effort to "tighten up" the relationship between inputs (funding) and outcomes without fundamentally altering the basic nature of the traditional government-to-agency block funding model.

In the Canadian context, family members of people with intellectual disabilities developed the notion of Individualized Funding in British Columbia in the late 1970s. Operated on a pilot basis under the Community Living Society, whose parent-led pioneering work had a major influence on the work of the TSC, Individualized Funding was a response to the experience of family members that traditional models of service delivery in the developmental services sector had been either unable or disinclined to effectively address the support requirements of people with complex needs or who were otherwise "hard to serve".[79] Failure of the community system to adequately respond to needs in turn resulted in institutional placements, especially for people with pervasive or complex support requirements (e.g., for personal care, attendant service, behavioural/emotional support, communicative assistance and assistance with a range of everyday activities such as meal preparation, participation in community activities and so on).[80] Individualized Funding was conceived as a systems tool that would allow for the allocation and management of public funds to bring into play the human, technological and other supports to address specific needs on a person-by-person basis in the community.

If Individualized Funding was understood to be a tool that was to assist in the development of new support arrangements instead of expecting individuals to "fit" into pre-existing service arrangements that may not have been appropriate or preferred (e.g., a group home "bed" or a "day program" managed by a service providing agency), Individualized Funding was also seen as a tool to assist in the development of suitable community support options as *alternatives* to institutional placements.

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[79] See, for instance, Woodlands Parents Group (August 1983). "The Story of the Woodlands Parents' Group: Personal and Organizational Perspectives". Vancouver: Author; M. Rioux and C. Crawford (1983). *Choices: The Community Living Concept is a Way of Thinking*. Vancouver: Community Living Society; The [G. Allan] Roeher Institute (1987). *Service Brokerage: Individual Empowerment and Social Service Accountability*. Downsview: Author.

[80] In the "early days" of community-based service delivery in the developmental services sector, insitutionalization of people whose needs could not or would not be addressed by service providers was the only practicable option for family members no longer able to continue providing round-the-clock support to individuals with extensive support requirements.

As a concept, Individualized Funding was anchored in principles such as the dignity and value of all people regardless of severity of disability, individual empowerment and self-determination, choice, flexibility, system responsiveness, social inclusion and ensuring basic safety and security while respecting the dignity of risk. It was also anchored in the recognition that some people need assistance in planning for and in securing the supports needed for life in the community, and that the planning function should serve as the agent of the person requiring funding. The latter involves that the planning be as separate as possible from the funding body in order to reduce conflict of interest.[81]

Individualized Funding was implemented under various programs in British Columbia through the 1980s and 1990s.[82] Since its inception, it has been piloted in most provinces in Canada and many western countries, including the United States, United Kingdom, Australia, New Zealand and Italy. Prince Edward Island has moved forward with an Individualized Funding approach in its provincial Disability Supports program.[83]

Positive experiences with Individualized Funding were related in the course of the interviews; documented stories can be found in *Towards Empowerment: A Glimpse of the Future.*[84]

Having said this, however, some families' experiences with Individualized Funding were not so favourable. In part this was due to the particular implementation model to which they had been exposed.

A knowledgeable interview respondent with significant background in this area summed up three quite different approaches to Individualized Funding that have been confused theoretically and operationally.

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[81] M. Rioux and C. Crawford (1983). *Choices: The Community Living Concept is a Way of Thinking.* Vancouver: Community Living Society; *The* [G. Allan] Roeher Institute (1987). *Service Brokerage: Individual Empowerment and Social Service Accountability.* North York: Author.

[82] E.g., Community Brokerage Services Society, Microboards, Choice in Supports for Independent Living.

[83] See Prince Edward Island, Health and Social Services (Undated - 2002?). *Prince Edward Island Disability Support Program Handbook.* Charlottetown: Author.

[84] Community Living Brokerage Society (Undated). *Towards Empowerment: A Glimpse of the Future - The Story of Individualized Funding and Autonomous Service Brokerage.* Vancouver: Author.

- In one approach, a person's needs and strengths are identified, support implications identified, and dollars are allocated to arrange for supports to address needs and build on strengths. As needs vary, so would levels of funding.
- At the other end of the spectrum, people are paid a flat rate that may bear little or no relation to needs. Some get more money than required, and others get less, in some cases much less than is needed.
- In between these two extremes is an approach in which people are assessed for funding-eligibility according to a three or four funding "levels". For example, people assessed as having a profile that meets the eligibility requirements for "level one" funding would get less than people who qualify for "level two", and so on through the levels. This is like a graduated flat rate system.

Each approach has strengths and limitations, which are beyond the scope of this research to detail. Generally, however, the first approach has the potential to tie dollars to needs in a highly sensitive fashion, but can be administratively costly in the sense that considerable time and effort may be required to identify and keep abreast of those needs. If there is no upper end "cap" on the eligible amount, per person costs can be quite high for some individuals.[85] The flat rate approach is administratively less expensive and easier to control from a fiscal perspective, but may bear little relation to actual needs.

In addition, some people may need and want little in the way of assistance with managing the disbursement of funds, tracking and accounting for disbursements, hiring and training personnel to meet needs, meeting payroll requirements (e.g., statutory deductions) and so on. In fact, they may want and may have the capability to assume full self-management responsibilities. Individualized Funding directly managed by the person with a disability (or their family/network) has been called Direct Funding. Direct Funding is provided under the BC Ministry of Health Services' Choice in Supports for Independent Living (CSIL) program for adults who are eligible for home support services. MCFD makes available direct funding to families and children through the At Home Program and Autism initiatives.

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[85] A government official quite knowledgeable about Individualized Funding indicated that the overall costs of the system as a whole, however, can be quite reasonable. While some people will need more than the "average" amount of funding for supports, other people will require much less, all of which balances out in the end.

However, other people may need considerable assistance with the administration of individualized dollars – or may want to have as little as possible to do with such functions and responsibilities.

It was evident in the interviews that some people had been exposed to a "flat rate" approach. The approach came nowhere near meeting the needs of their disabled family member or of themselves as parents with significant care giving responsibilities. The approach involved significant administrative responsibilities for themselves and the services needed were not as available as would ideally have been the case. In short, these people did not have good experiences with the model of Individualized Funding that they had encountered. Asked one exasperated interviewee, "Why can't I just be a mom for my child?"

IV. Key Government Initiatives

In the summer and early fall of 2001 the government initiated its Core Services Review and announced significant funding cuts. These developments created a sense of urgency among family members and other advocates involved with people with intellectual disabilities, who were spurred to mobilize and propose their vision for a renewed community living services system.

A. Core Services Review and Ministry Service Planning Initiated

Upon coming into power the new Liberal government introduced personal and business income tax cuts. In July of 2001, the government initiated its Core Review of government services and programs with a view to determining whether they met key criteria: serving a compelling public interest, affordability within the fiscal environment, effectiveness, efficiency and accountability and whether service provision reflected a legitimate and essential role for the provincial government.[86]

These developments marked the beginning of the Liberal government's Service Planning for all Ministries. [87]

B. Major Program Cuts Announced

In the summer of 2001, the new government amended the *Budget Transparency and Accountability Act* (Bill 5).[88] The legislation required annual budgets for all ministries, statements of underlying budgetary assumptions, a description of arrangements for public input to the budgeting process and oversight by a committee to ensure that the budgeting adhered to Generally Accepted Accounting Principles. Effectively, the new *Budget Transparency and Accountability Act* required strategic plans and annual performance reports on those plans by all ministries.

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[86] Premier Gordon Campbell (July 31, 2001). Letter to Ministers; Government of British Columbia (August 2, 2001). "Guidelines for the Core Services Review". Victoria: Author.

[87] About a year before, in July of 2000, the then NDP government introduced the *Budget Transparency and Accountability Act*. [SBC 2000] Chapter 23, Assented To July 6, 2000. The legislation committed government to develop an annual strategic plan and ministries to prepare annual service plans. All such plans were to span a three-year time horizon.

[88] August 13, 2001.

Also in this timeframe, the new government introduced the *Balanced Budget and Ministerial Accountability Act.*[89] That piece of legislation prohibited budget deficits from fiscal 2004/05 afterwards on pain of a 20% salary reduction for Ministers who fail to meet this obligation, half of which would be due payable the day after their budget is tabled.

The fiscal context for these pieces of legislation was the looming budget deficit. The magnitude of the deficit was reflected in the Ministry of Finance's First Quarter Forecast, released in the middle of September 2001. The Forecast attributed the weakening fiscal situation of the province and the projected deficit of nearly $2 billion to declining energy prices, a loss for the Insurance Corporation of British Columbia (ICBC), adverse effects of the countervailing duties imposed by the US on softwood exports, spending pressures within the Ministry of Health Services and uncertainty associated with planned economic growth.[90]

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[89] [SBC 2001] Chapter 28 Assented To August 16, 2001

[90] British Columbia, Ministry of Finance (September 13, 2001). *Summary – First Quarterly Forecast, 2001-02.*

In September 2001 the Premier and Minister of Finance signalled the government's intention to make major cuts to all ministries except Education, Advanced Education and Health. The cuts were to vary from 20% to 50%, with the average at 35%.[91]

Outlined in February 2002 in MCFD's *Service Plan*, the cuts would involve a 22% planned reduction in the number of MCFD staff, a 41% expenditure reduction for Corporate Services (Program and Regional Operations), a 17% funding reduction for Adult Community Living Services, and an 11% funding reduction for Early Childhood Development and Special Needs Children and Youth.[92]

C. MCFD Opens Up Core Service Review for Public Input

In early October 2001, MCFD opened up its Core Review for public input. It was the only ministry to do so.

Documentation provided to the public laid out six strategic shifts that the MCFD was undertaking:

- Open, accountable and transparent relationships.
- Enabling communities to develop and deliver services with a consolidated, comprehensive, community-based service delivery system.
- Strategic investments in capacity and resiliency building with evidence based funding.

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[91] Premier Gordon Campbell (September 27, 2001). Speech to Union of B.C. Municipalities Convention, Vancouver. See also a chronology at http://www.bcpolitics.ca/left_timeline.htm and New Democrat Joyce McPhail's reaction at http://nid-275.newsdetail.bc.ndp.ca/.

While the ministries of Health and Education were exempted from the cost-cutting scenarios, the government committed to wage settlements with doctors and nurses that would amount to about 20% over a three-year period. Only the first year's increases were funded. Remaining funds had to be found from the ministries' base budgets. Service reductions were means of channelling funds to salaries, which had the same practical effect as funding cuts for education and health services.

Later, the government would reverse the Munroe Award (Bill 29 – 2002, *Health and Social Services Delivery Improvement Act*) January 27, 2002.

[92] British Columbia, Ministry of Children and Family Development (February 2002). *Service Plan 2002/2003 to 2004/2005*. Victoria: Author, p. 16. By way of contrast, there was to be a 30% funding reduction for Child Protection and Family Development and a 22% reduction for Youth Justice, Child and Youth Mental Health and Youth Services.

- Promoting family and community capacity to protect children and to support child and family development.
- A community based service delivery system for adults with developmental disabilities that promotes choice, innovation and shared responsibility.
- Building capacity within Aboriginal communities to deliver a full range of services, with emphasis on early childhood and family development.

Two questions for which the ministry was seeking answers were:

- Are the current organizational and service delivery models the most efficient way to manage and deliver the program, activity or business unit?
- Are the current measures and reporting mechanisms the most effective way to account for program, activity or business unit performance (relevancy, effectiveness, service)?[93]

The document stated that, "About half of the ministry's $1.56 billion budget supports this service area [i.e., for people with developmental disabilities], largely through the contracted community sector. The budget needed to support the service is projected to grow at an unsustainable rate, at about four per cent per year. It is likely that the $60,000 per client placement cost could be used much more effectively if the system offered choices to families, to communities, to private and community sector partners."[94]

MCFD had also put into the public domain a Discussion Paper on community living services in October 2001. Its analysis of the situation that needed to be addressed included the incompatibility of the child welfare and community living cultures within the ministry, the financial unsustainability of present arrangements, the disempowerment of individuals and families under traditional approaches and the need for innovation based on "community involvement and governance, ownership and accountability, local decision-making, transparent processes, reduced bureaucracy and deregulation."[95]

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[93] British Columbia, Ministry of Children and Family Development (October 2001). *Core Services Review*. Victoria: Author.
[94] Ibid., p. 6.

Other key points included MCFD's intention to devolve services and decision making to communities, citizenship as a policy framework, the place and importance of personal relationships, and empowerment and individualized funding as means of promoting and safeguarding security and quality of life. The document also touched on the role of non-profit and for-profit service providers, and the need for partnerships among various players (individuals, families and other caregivers, communities, governments, service providers and the business sector) in meeting the needs of people with disabilities. [96]

MCFD indicated in the Core Review document that it would receive submissions up to October 31, 2001. This gave the community less than a month to respond. The real timeframe was even tighter in that MCFD had to have its plans ready for submission to the Core Services Review Panel by the end of October.

In addition to the tight time frame, submissions were to be sent to a Website that the Ministry had established for that purpose. While MCFD was the only ministry to open itself up to submissions to its Core Review, and many people did participate in the process, not everyone in the community living sector had access to computers and as a result some felt shut out of the consultation.

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[95] British Columbia, Ministry of Children and Family Development (October 2001). Discussion Paper on Community Living Services, p. 5.
[96] Ibid., pp. 5-6.

V. Developments at the Community Level

As the government's Core Services Review and funding cuts rolled out, there was a mobilization of individuals and organizations at the community level. This section of the report provides a look at those developments.

A. Emergence and Position of the Individualized Funding Family Coalition

1. Individualized Funding Network

Over the years before the Liberal party's coming to power, a small group of people who had been involved in early pioneering efforts around Individualized Funding had continued to maintain personal and professional ties. A group of families had continued to advocate for Individualized Funding throughout the 1980s and 1990s. The Individualized Funding movement grew stronger during the 1990s, culminating in a number of Family Summits from 1998 through 2000 that drew parents together from around BC and in the First International Conference on Self-Determination and Individualized Funding, in Seattle, Washington at the end of July 2000.[97]

Individualized Funding was discussed at the family summits. There were tensions in those discussions between the philosophies of self-direction and supported self-direction, approaches that drew interest and support from the independent living and the community living movements, respectively.

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[97] A Provincial Steering Committee on Individualized Funding, organized by the BC Coalition of Persons with Disabilities, included 21 organizations in 1998: Alzheimer Society of B.C., Amyotrophic Lateral Sclerosis Society of B.C., Autism Society of British Columbia, B.C. Association for Community Living, B.C. Coalition of People with Disabilities, B. C. Paraplegic Association, B.C. Rehabilitation Society, Cerebral Palsy Association of B.C., COPE-HMD, Coalition to Promote Interdependent Living, Council of Senior Citizens' Organizations of B.C., Familiy Link Society, Family Support Institute, Multiple Sclerosis Society - B.C. Division, Muscular Dystrophy Association of Canada, Planned Lifetime Advocacy Network, Vela Housing Society, West End Seniors' Network. Available at http://www.bccpd.bc.ca/if/updocs3/steering.html.

With the impending provincial election, people who had been networking and conversing around Individualized Funding recognized that community living in BC was at a crossroads. We heard in the interviews that people understood full well that government was going to make decisions that would potentially have profound impacts. There were essentially two options for family members and other advocates: 1) try to shape government's decision making and work with the decision makers, or 2) be at the receiving end of the decisions without any say and live with the consequences.

Accordingly, about fifty people from across the province who had been conversing and networking on Individualized Funding met in August 2001 to develop a position for presentation to the government. This meeting marked the inception of the Individualized Funding Family Coalition (IFFC), which embarked upon broader community consultations. The VanCity Community Foundation and the Vancouver Foundation provided funding for those consultations.[98]

2. Community Governance Network

Some of the promising developments in the community living sector in the 1980s and 1990s were the result of people taking control of their own affairs. Interest developed in the late 1990s in removing community living services from government and having it managed entirely by the community, i.e., community governance.

People who had been working on these ideas also recognized that, with the impending provincial election of 2001, there was an opportunity to shape government decision making, and if this opportunity was not seized, decisions would be taken and the consequences would have to be borne. Said one interview respondent who was quite involved in discussions on community governance, "In order to make Individualized Funding survive you'd have to take over the entire system. You had to transform the entire culture or Individualized Funding would be marginalized."

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[98] Reference available at http://www.individualizedfunding.com/IFFC_Family_Leadership_in_BC.htm.

A few people who had been holding conversations on community governance set out to convince leaders in the IFFC network that they'd have to think larger and take on more than they may have wanted to. Reportedly, several leaders in the IFFC network, like most other family members who comprised the IFFC, were initially opposed to idea of taking over the entire system; tensions had reportedly persisted for about a year before the summer of 2001 between these people and those who were in favour of community governance.

Meanwhile, people pursuing the notion of community governance were getting a reading of what Liberals in opposition would do when in government. As the Liberals articulated their vision, leaders pursuing community governance began to use the Liberals' language to describe community governance in terms such as decentralization, community control, private/public partnerships and so on.

Those leaders also began to send out feelers to service providers in the community living sector. Some service providers reportedly got quite excited about service reform, getting "back to basics" and about increasing service responsiveness to families and individuals. Several meetings were held between leaders pursuing community governance and a few executive directors of large service organizations in the community living sector.

3. Coming Together of the Two Networks

People interested in Individualized Funding and community governance continued to meet, and by the end of the summer of 2001 the IFFC had expanded to include about 75 leaders from across the province. There was mutual recognition that it would be counterproductive to be presenting conflicting messages to government. Two of the leaders had a frank conversation on where the differences lay between the Individualized Funding and community governance camps and figured out areas where compromise was possible. In September several leaders began meeting with a view to putting together a compromise position statement that would integrate Individualized Funding and community governance. A draft document served as basis for community dialogue for about a month.

Reportedly, a major concern in the drafting was that the setting up of a community governance entity could have the practical effect of taking on responsibility for managing provincial downloading and cuts and would create a buffer between government and the community.

As the month of September unfolded, that joint work was reportedly driven as much by concern about the potential impacts of cuts as by desire to implement a new service and governance paradigm. By early October those efforts had culminated in, "A Policy Framework to Guide the Implementation of Individualized Funding for Community Living Services in British Columbia", which subsequently became known within the IFFC as the "Framework Document".

That document reflects the language of rights, equality and self-determination, flexibility and innovation in approaches to support, and the participation and contribution of people with developmental disabilities as valued equals in personal relationships in their community.

Other key principles included in the document are that individuals and families would be involved in the policy process, community governance would be accountable to individuals and families, and that government would have ongoing responsibility for ensuring that resources are in place to meet needs. The governance structure was to be responsible for multi-year planning, for cost-recovery and for negotiating with government for funding allocations. Individuals and families would have access to planning supports that were to operate independently from government and service providers. As well, there was to be a legislative base for Individualized Funding. Government ministries providing community living supports were to be involved in the transition to the new model and thereafter, and new arrangements were to be cost-neutral in terms of new costs beyond the transitional period.

The stated single purpose of community governance would be "to implement individualized funding".[99] This would involve the transfer of responsibility for disability policy and service systems to community governance, government creation of policies that establish Individualized Funding as "the means"[100] by which financial resources were to be provided to individuals and families, and implementation of Individualized Funding across the province.

The document envisioned a sweeping change in the way community living services were to be organized, funded and delivered.

Some of the people we interviewed perceived the IFFC to be mainly a Vancouver Lower Mainland phenomenon and that the vision presented in the Framework Document concerning services may have been pertinent for the Lower Mainland but not necessarily for other communities.

Others indicated that they had intended that Individualized Funding would be positioned as a desirable addition to the suite of service and funding options, but not the only or preferred modality. The Framework Document, however, does not frame Individualized Funding as one option among other modalities, but rather as "the means" of allocating financial resources for community living supports.

B. Position of BCACL

In its response to the new Liberal government's Core Services Review of 2001, the British Columbia Association for Community Living (BCACL) provided a critique of the current situation of community living services that included wait lists and lack of government consultation prior to major structural changes to the service system. It pointed to full citizenship as the policy framework that should guide service delivery, as well as to improved access to services, portability, consumer control and greater responsiveness to individual needs. BCACL called for personalized, integrated, comprehensive, flexible services to address needs across the life span and through life transitions. Eligibility was to be based on need for support. Planning and other supports were to be accountable to and respectful towards people with disabilities and their families. Supports were to be person and family-centred, under the control and direction of individuals and families.

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[99] Individualized Funding Family Coalition (October 4, 2001). *A Policy Framework to Guide the Implementation of Individualized Funding for Community Living Services in British Columbia.* Vancouver: Author, p. 2

[100] *Ibid.*

BCACL also called for cross-ministerial responsibility to further the equality and citizenship of people with disabilities, with MCFD playing a lead role.

While acknowledging the need for fiscal accountability, the submission expressed concern about the "severe toll" that elimination or reduction of community living programs would cause for individuals and families. It expressed scepticism about whether massive restructuring would result in significant cost savings, and pointed out that, while building natural supports was a laudable goal, individuals and families were already relying to the maximum of their ability on their own resources. BCACL argued that more flexible funding options for individuals and service providers would open opportunities for proactive supports, thus avoiding unnecessary future costs. The submission also called for the elimination of rigid bureaucratic approaches to budgeting.

BCACL agreed with a provincial Joint Committee (discussed below) that individualized funding should be available as an option to individuals and families who want it, as should independent planning supports, and greater portability of various supports. However, the submission pointed out that not all families want or need such an approach and, effectively, that families who are satisfied with present arrangements should be left to those arrangements. The submission called for continued availability of services provided by community organizations and for the protection of workers' rights to fair working conditions, wages and benefits.

BCACL's submission also called for fairer approaches to eligibility determination. Observing that recent changes to governance since the *Gove Report* had not resulted in improved service delivery or enhanced citizenship for people with disabilities, the submission called for a service delivery structure that safeguarded and enhanced provincial accountability, participation by individuals and their families, process for conflict resolution and appeals, provincial advocacy for service quality and continuity of expertise and knowledge in any new governance arrangement.[101]

C. Other Coalitions/Networks

As well as the IFFC, several other family networks and consultative bodies had been developing in BC.

The Family Support Institute is a provincial non-profit working organization, originally started under the auspices of BCACL, to support and strengthen families who have children with disabilities. It facilitates parent-to-parent networking through a model of self-help and mutual aid. It has about 160 volunteer families across BC, all of whom are parents of children with disabilities.[102]

BC FamilyNet is an independent provincial network that provides a provincial voice for children and youth with special needs and for adults with developmental disabilities and their families. It was formed in 1995 out of concern that the government was failing to keep its promises to consult with the community and to avoid disruption of services when the Ministry for Children and Families (MCF) was moving forward with its massive restructuring of services under the previous NDP government. FamilyNet has continued to monitor developments within the community living sector, pushing for action on waitlists, portability of services within the province and for transition services for young people moving into adulthood. [103]

A Provincial Community Living Council had been established by MCFD in 2000 in response to an audit of residential programs for persons with disabilities.[104] The Council was intended to provide advice and expertise to the ministry on policies, programs, practices and principles for services for adults with developmental disabilities and children with special needs.

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[101] BC Association for Community Living (October 2001). "The Ministry of Children and Family Development's Core Services Review: Response and Recommendations from the BC Association for Community Living". Vancouver: Author.

[102] http://www.vcn.bc.ca/fsi/

[103] http://www.bcfamilynet.org/history.html

The ministry had also established Regional Community Living Councils in eleven regions to provide advice to regional management for the planning, development and implementation of regional community living services.

A Community Living Action Committee (CLAC) had been established in 1999 in response to impending funding cuts that year. It comprised the BC Association for Community Living, the Family Support Institute, BC FamilyNet, the Provincial Community Living Council, BC Pricare (a coalition of private care providers), the BC Association for Child Development and Rehabilitation, and the Community Residential Service Providers of BC. Also sitting on the committee were regional and headquarters staff of the Ministry for Children and Families and the Ministry of Health, including representatives from the MCF Deputy Minister's office and the Advocate for Service Quality.[105]

The broader disability community was represented by the BC Coalition of Persons with Disabilities, which comprised mainly but not exclusively the voices of people with physical disabilities.

It is beyond the scope of the present research to detail the positions of these organizations concerning the emerging policy and program context.

D. Position of the Joint Committee

A "Joint Committee" was initially established in 1996 and consisted of representatives from the Family Support Institute, BC FamilyNet, Families for Mentally Handicapped People, Infant Development Programs of BC, the BC Association for Child Development and Rehabilitation, Community Residential Service Providers of BC, BC Pricare, the Autism Society of BC, BCACL, the

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[104] British Columbia, Ministry for Children and Families, Deputy Minister (February 10, 2000). "Deputy Minister's Response "Re: Residential Programs - Persons with a Developmental Disability Audit Report". Victoria: Author.

[105] The Advocate for Service Quality was appointed by the NDP government to build understanding of the community living sector within MCF and to develop and support MCF's linkages with the sector.

BCACL Self Advocacy Caucus and individual family members. The Joint Committee was formed to follow up on the recommendations of the *Gove Report* and provided a forum for representatives from the community living sector to address issues related to the service delivery system. Its goal was to ensure children with special needs and adults with developmental disabilities in British Columbia had the services and supports they required to live and thrive in community throughout their lifetime.

The Joint Committee submitted a document to MCFD in response to the Core Services Review in October 2001 that laid out a critique of the current state of community living services and which presented an alternative vision. The critique included reference to inconsistent implementation of service delivery principles, lack of individual choice in planning and implementation of supports, lack of funding and commitment to meet individuals' needs, unacceptable wait lists, dilution of services, cutbacks, lack of continuity in service for young people over 19 years, stresses and strains on families, lack of cost-effectiveness of services, service inequities stemming from inconsistent interpretation of policy and lack of accessible information about available support services.[106] The critique echoed an earlier document entitled "Hitting the Wall", which organizations within and beyond the Joint Committee had submitted to government in 1995.[107]

The solutions proposed were based on principles of individualized planning and lifelong support, choice and portability of services and supports, consultation and communication with individuals and families in decision-making about the services and supports they use, proactive and flexible services to optimize lifelong chances for learning and community inclusion and to prevent crises and family breakdown, availability of adequate resources and cross-ministerial collaboration for better coordination of responsibilities across government ministries. As well, principles advocated adherence to MCFD's own service delivery principles, provincial standards for access to service and accountability measures that were not only fiscal in nature but that included accountability of government to children, youth, adults and families who require supports.[108]

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[106] Joint Committee (2001). "Joint Committee Response to Ministry of Children and Family Development Core Services Review October 2001". Vancouver: Author.

[107] Coalition for Community Service Provision for People with Disabilities (November 1995). "Hitting the Wall" A Brief. Vancouver: Author.

In terms of governance, the Joint Committee favoured government retention of responsibility for policy development, funding and accountability functions, as well as for the development of provincial standards, outcomes and monitoring/accountability mechanisms for service delivery.

It favoured the notion of independent planning and support for families that could be accessed at the community level, which would eliminate the need for the MCFD social worker function in the process. The Joint Committee also recommended elimination of the MCFD regional management function and structure as that system, in the Joint Committee's view, lacked accountability to the community.

The Committee supported a phased-in model of Individualized Funding, beginning with the expansion of respite services for children and for adults, as well as for life skills and self-help services.

However, the Joint Committee considered unacceptable any further devolution of the government's responsibility for ensuring adequate funding, provincial standards and monitoring of service delivery. Instead it favoured the model of community governance already at play in the non-profit services sector through agencies' voluntary boards of directors who were accountable to recipients of services and to funders.

E. Position of the Service Provider Network

For their part, several other service providers in the community living sector appreciated the seriousness of the fiscal and program context and were meeting with one another in the summer of 2001. At a meeting with the then Assistant Deputy Minister of MCFD in July they discussed the role of the social worker, the problem of multiple regulatory bodies, labour relations, information management and Individualized Funding.[109]

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[108] *Ibid.*

At a subsequent meeting in August they discussed similar themes and provincial accreditation,[110] mutually agreeing that it was "absolutely necessary for service providers to come together and to develop a coordinated response to the discussion on core service review process and governance initiated by the new government – that this represented a real opportunity for change and … that the status quo was not an option." They expressed the view that "Tinkering with what currently exists is not an effective method for substantive change. Instead we propose to wipe the slate clean and design a new system to respond to adults with developmental disabilities' need for community support." Principles to guide these service providers' approach included consumer choice (of service options and service providers), encouragement and stimulation of innovation, affordable and accountable program measures, decision-making brought closer to the community, individualization of services and funding, and portability.[111]

They also agreed to "coordinate our efforts with the group promoting individualized funding" and "to attempt to consider alternative points of view in our consideration, including parents, self advocates, private service providers and MCFD staff".

At their meeting on September 4, 2001, the network of service providers laid out their strategy for developing a submission to the Core Review, including time lines and key messages.[112]

The submission of the service providers reflected their discussions of August, and included further points. These included the need for more service options for individuals with developmental disabilities and their families, more consumer choice of service providers, more and better information about services available and service standards to inform decision making, clear outcomes to ensure value of services to families and taxpayers, needs-based funding, measures to ensure accountability for costs, and fairer process for eligibility determination. The submission touched upon the roles of families, service providers and government in governance arrangements for alternative models of service provision.[113]

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[109] Vision for Community Living (July 17, 2001). "MCFD Deregulation Meeting with BCACL Executive Directors – Summary Notes". Vancouver: Author. Available at http://www.visionforcommunityliving.com/deregulation0701.htm.

[110] Vision for Community Living (August 24, 2001). "Ad Hoc Meeting of Executive Directors of BCACL – Summary". Vancouver: Author. Available at http://www.visionforcommunityliving.com/aug24summary.htm.

[111] Ibid.

[112] Available at http://www.visionforcommunityliving.com/archive.htm.

On October 2, 2001 the service providers submitted to MCFD's Acting Deputy Minister their *Service Provider Submission – Core Services Review*. They stated in their covering letter, "While we do not have a mandate to speak for all service providers, the process we utilized for compiling this brief provides reasonable assurances that the views contained within it correspond to those of the majority of service providers. This is most particularly the case with respect to our definition of 'core services' and issues and recommendations relating to the 'governance' of the social services sector."[114]

They defined core services as comprising child development/early intervention services for children with special needs, support to families of children and youth with special needs living within the family home, support to children, youth and adults for skill development and the achievement of personal goals,[115] employment, training and/or daytime support for adults with developmental disabilities, support to families who continue to act as primary caregivers of adults with developmental disabilities and residential options for adults and children who cannot live with their families.

The approach to governance was based on a vision of individual rights and citizenship, access to the same life choices generally available to other community members, support for individuals and families to solve their own problems, choice of services and service providers, involvement of families and friends in planning, stable and consistent continuum of services that enable smooth life transitions, portability of services across the province and community support as an essential dimension of support to individuals and families.

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[113] Vision for Community Living (September 2001). "Agenda" for meeting, September 4, 2001. Available at http://www.visionforcommunityliving.com/V4CLProcess.htm

[114] Both the cover letter and submission were available at http://www.visionforcommunityliving.com/vision_4cl_final.htm.

[115] e.g., increased independence, greater community participation and contribution, development and maintenance of friendships.

System principles reflected those values and included the need for personalized services and direct funding, and inter-ministerial funding and coordination arrangements that would enable personalized approaches, service portability and sustainability. Governance arrangements were also to involve decentralized, community-based decision making, responsibility for services to children and adults under one authority outside of a child protection framework, less focus on government control and micro-management and more focus on outcomes. The submission's service principles revolved around themes of availability, family-centred and individualized approaches, recognition of and assistance to families in their key role as providers of support, social integration and inclusion as guiding values for services, quality assurance based on consumer feedback and provincial service standards.

Government was to establish the mandate of the system and set policy for eligibility determination and funding levels. A Provincial Community Living Board (PCLB), consisting of individuals, family members, service providers and community/business members, was to have direct responsibility for, among other things, setting provincial service standards, determining eligibility for funding and services, distributing funding to individuals and families, providing for advocacy and conflict resolution of people supported, and delegation of various service and community development functions to community employees.[116]

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[116] Vision for Community Living (October 2, 2001). *Service Provider Submission – Core Services Review*. Vancouver: Author.

VI. Formation of the Community Living Coalition

The individuals and organizations that came together in earnest in the summer of 2001 eventually coalesced in an unprecedented show of cohesion in the Community Living Coalition. The Coalition developed and submitted a proposal on community governance and service arrangements that lay the foundation for the work of the Transition Steering Committee. This section of the report provides an overview of the consolidation and policy position of the Coalition.

A. Consolidation of the Coalition

Prior to the end of October 2001, BCACL was not at the table with the IFFC; there was some scepticism on the part of the BCACL Board and some people within the ACL federation felt nervous about the alignment of leaders in the IFFC with the new government. Several service providers began to put pressure on BCACL to take part in discussions with the IFFC, indicating that they were prepared to withdraw membership from BCACL. However, the service providers eventually became convinced that polarization within the BCACL federation would not serve a useful purpose.

On October 25, the BCACL Executive Directors' Network invited members of the IFFC to present their proposal and considered it in view of the proposal of the service providers' network, the Joint Committee and that of BCACL. They found many similarities and agreed to support the emerging coalition in promoting the new governance model in response to the Core Review and to conduct province-wide meetings to bring together service providers to discuss key elements of the response within the context of major cuts.

Meanwhile, the Community Living Coalition was formalized on November 1, 2001. It consisted of the IFFC, the Service Providers Group (subsequently named Vision for Community Living) and the Joint Committee.

By November 5 the BCACL Board of Directors had agreed to support the Coalition's efforts, recognizing the importance of a new governance model. The Board committed to keeping services for children and adults together, and to maintaining then current funding levels for community living supports and services.[117]

The IFFC, the Service Providers Group, the Joint Committee and BCACL are named as founding members in the minutes of the Coalition's first meeting on November 8, 2001.

Figure 2 provides a diagram of the coming together of these organizations.

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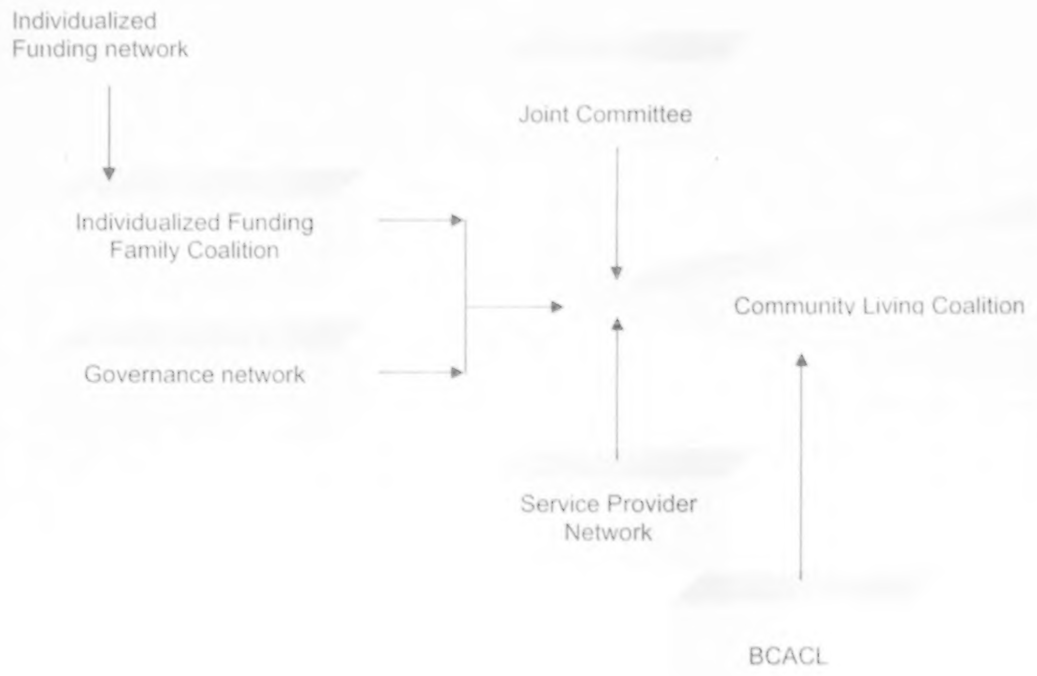
[117] Community Living Coalition of B.C. "History of the Coalition". Available at http://www.communitylivingcoalition.bc.ca/history.htm. See also http://www.visionforcommunityliving.com/BCACLGovernance.htm

Figure 2. Formation of the Community Living Coalition


Individualized Funding network
Joint Committee
Individualized Funding Family Coalition
Community Living Coalition
Governance network
Service Provider Network
BCACL

The basic policy position of the Coalition, circulated at that meeting, underscored the need for:

- The then present range of services to remain as core services;
- Provincial policy and standards;
- Government responsibility for providing adequate funding;
- Individualized funding as an option;
- Changes in the role and function of the social worker;
- Some form of independent service planning (i.e., de-linked from service provision and government);
- Cross-ministerial cooperation and total government commitment (i.e., not just MCFD) to Community Living;
- Vision and social policy;
- An appeal process;
- Family involvement in governance; and
- Responsibility for children and adults' community living services to be kept under one administrative structure.

The positions were also stated that any efficiencies to be gained from the community living services system could not be derived from direct service cuts, that there should be no decrease in community living funding and that a governance model must come with not only responsibility but with authority.

As well, all funding, government staff and resources for community living for adults and children were to be transferred to a single governance entity, which, it was stated, would result in savings that in turn were to be used to address wait lists.

Other discussions at that meeting revolved around the concern about the possible shift of all children's services either to child protection or to the Ministry of Health, financial caps on individualized funding, involvement of others in the coalition, and the need to address the ministries of Education and Human Resources. The latter ministries had major involvement with people with developmental disabilities and were also operating under the regime of funding cuts.

Two key messages for government that emerged from that meeting [118] were the potentially devastating impact of cuts on people's lives, and the need to keep together community living services for children and adults. These concerns persisted in the Coalition for many months afterwards.

The Coalition subsequently held meetings about every two weeks to address funding cuts, to develop a new governance structure for community living and to promote Individualized Funding as an option for individuals and families.

Throughout the month of November 2001, Coalition members engaged in a flurry of letter writing and meetings with provincial Members of the Legislative Assembly.

At the Coalition meeting of November 15, 2001, however, a fault line began to open. The BC Association for Child Development and Rehabilitation (BCACDR), which was a member of the Joint Committee, took the position that services for children who require extra support would be better positioned with other children services. While BCACDR agreed that such services should not be under the jurisdiction of child protection, it did not agree that they should be located with services to adults. That position varied from that of the Coalition's position that services for children with special needs and adults with developmental disabilities should stay together. Several Coalition members agreed to meet with representatives from BCACDR to discuss the issue in more detail.[119]

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[118] Community Living Coalition of B.C. "Minutes, Nov. 8, 01". Available at http://www.communitylivingcoalition.bc.ca/minutes110801.htm.
[119] Community Living Coalition of B.C. "Minutes, Nov. 15, 01". Available at http://www.communitylivingcoalition.bc.ca/minutes111501.htm.

B. Community Living Coalition's "Community Governance Proposal"

Throughout November 2001, a small team of people who had been involved in the development of the IFFC's Framework Document, as well as some members of the service providers group and the Joint Committee, worked on the Coalition's *Transforming Community Living Services: A Proposal to the Minister of Children and Family Development*. Interview and focus group respondents for the present research referred to the document as the Coalition's "Community Governance Proposal".

Policy objectives stated in the document were to:

- Take government out of direct service delivery to children and adults with developmental disabilities;
- Create a new governance structure for the delivery of supports to individuals and families;
- Review policies and regulations to remove barriers to individuals, families and communities finding their own solutions to the challenges they face;
- Provide a choice of Individualized and Direct Funding to help individuals and families to meet their own needs;
- Encourage and acknowledge through the tax system new sources of funding from the community, corporate sector and families;
- Enable government to meet budget and staff reduction targets, redirecting funding saved for individuals and families on wait lists.[120]

The key funding and expenditure objective was to reduce the cost of providing community living and related services by twenty percent over three fiscal years (from April 1, 2002 to March 31, 2005) and to redirect the savings to provide support to people on wait lists.

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[120] The Community Living Coalition (November 30, 2001). *Transforming Community Living Services: A Proposal to the Minister of Children and Family Development*. Vancouver: Author.

This objective was to be achieved by reducing costs associated with government management and administration of contract services, reducing costs associated with the payment, administration and monitoring of funds flowing to direct services at the community level, streamlining existing community-level services to reduce administrative/management costs, and by providing funds directly to individuals and families to allow them to address their own support needs.

The proposed governance arrangement involved several principles and design features. Essentially, however, the new structure was to assume complete responsibility for all services to adults with a developmental disability and children with special needs. It would offer individualized funding and direct funding to families, integrated within a system intended to provide increased flexibility and portability, reduced administrative costs and that was to be focused on providing sufficient support to allow people to meet their own needs. It was also intended to work with non-profit service providers to jointly oversee the development of innovative, flexible support options and alternative individual and family support delivery models.

The structure was to have an on-going relationship with government, securing in the process a voice for people with disabilities and their families in policy development. It was to have a minister-level relationship with Treasury Board, an ability to carry forward surpluses from operational savings from one fiscal year to the next and operational decision-making autonomy.

To those ends, the structure was to be a Part II Federal Non-profit Corporation,[121] with the proposed name of "the Community Living Corporation of BC".

Government would maintain ownership of the corporation, including overall responsibility for funding and standards. The Ministers of Children and Family Development, Human Resources, Education, Health and Finance would be members and would appoint Directors. However, the corporation's Board of Directors would control operations, enforce standards and manage funds.

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[121] E.g., modelled along the lines of the Canadian Blood Services or similar non-profit corporation

Regional representation was to be based on five macro regions linked to the provincial structure, with one member of the Regional Advisory Body appointed Director of the corporation but limited to an advisory and volunteer role only. Local representation was to reside in a maximum of 15 local bodies, linked to the regional bodies and again limited to advisory and volunteer functions.

The provincial governance structure was to support the initiatives of Aboriginal communities to develop and deliver community living services. Other features of the proposal included a Second Level Core Services Review to determine: the cost-effectiveness of various public investments (e.g., home ownership for people with developmental disabilities, non-profit *versus* private care services); the regulatory, legislative, practice and other issues that prevent or penalize family or individual contributions; the requirements of culturally appropriate services; and the future relevance of then-funded services.[122]

A key idea put forward in the proposal was for government to use any savings to address the needs of waitlisted individuals and families. Government was also encouraged to: implement Individualized and Direct Funding as keys to system transformation within a general framework of citizenship and community capacity development; develop procedures for better outcomes management, accountability and fiscal accountability; address costs stemming from the Munroe Agreement and from children in care requiring various adult services; and engage families, service providers and communities in meeting government budget reduction targets.[123]

November was an important month because a critical mass of support emerged around these ideas. Two people in the Coalition's delegation to the Minister of that month characterized the process as "an unprecedented coming together of people with disabilities, their families, friends and service providers", resulting a "unity in the community living movement that has not been there in the last 40 years".[124] That view was echoed in several key informant interviews and in the focus groups.

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[122] According to one interview respondent, allusions in the document to community capacity development were "code" for service reform, home ownership for with intellectual disabilities, business development leading to genuine wages for people with intellectual disabilities and stimulation of volunteerism.

[123] *Ibid.*

C. Presentation of the Coalition's Proposal to Government and the Government's Response

A nine-person delegation from the Coalition presented the "Community Governance Proposal" to MCFD Minister Gordon Hogg on November 30, 2001. The Minister's initial response was reportedly "very encouraging".[125] Over the next few weeks he wanted further detail on the governance model. By mid-December it was evident that there was resistance within MCFD to keeping services to children and adults under one "roof"; MCFD reportedly wanted to keep all children's services together.[126]

The proposal went to Core Services Review on December 4, 2001 and to Cabinet on December 12. Cabinet reportedly endorsed the governance model based on the Coalition proposal. While Cabinet accepted the terms for a single provincial governance body, it was not in favour of regionalization.[127]

At its mid-December meeting, the Coalition staked out the position that it could go along with a 20 per cent cut if the savings would be funnelled back to address people on wait lists. However, there was also recognition that this would be a decision for Cabinet. The next Cabinet meeting was slated for the middle of January 2002.

By the end of January 2002 there was a sense among Coalition members who met with the Minister at the end of November that his initial enthusiasm had tempered somewhat.[128]

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[124] Community Living Coalition of B.C. "Update Nov 30, 01".
[125] *Ibid.*
[126] Community Living Coalition of B.C. "Minutes – December 14, 2001"
[127] *Ibid.*
[128] Community Living Coalition of B.C. "Minutes – Jan 31, 2002".

VII. MCFD's Service Plan and Implications for Transition

In the middle of January 2002, MCFD issued its "Service Plan Summary". The full *Service Plan* was issued in February. These plans further galvanized the Coalition.

Intended results to be achieved by "Strategic Shifts" included a more coherent community-based service system, investments in people's ability and potential to recover from challenging situations (i.e., capacity and resiliency), support for child and family development, services based on choice, innovation and shared responsibility, and expansion of Aboriginal communities' capacity to provide a fuller range of services with emphases on early childhood and family development.

Other goals and objectives for adults with developmental disabilities were for the ministry to work with the community to develop and implement a new governance and service delivery structure, standardize eligibility and assessment for community living services across the province and to develop additional supports and incentives including direct and individualized funding options so families could keep adult children at home as long as possible. The ministry was also to "encourage" families to contribute to the costs of adult services and planned to establish independent living and family care arrangements to replace staffed residential resources.[129]

The Plan also mentioned the government's intention to introduce "specialized cost effective residential resources…for adults with complex needs", which sent off 'alarm bells' among the Coalition. Already at the Coalition meeting on November 8 there had been concern about the Minister's musings on institutional care. The Service Plan Summary suggested that the ministry had moved beyond musing. It will be remembered that parents and other activists had made a major point of working to close institutions in the 1980s and 1990s.

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[129] British Columbic, Ministry of Children and Family Development (2002). "Service Plan Summary 2002/03-2004-05".

For services to children, the Ministry again committed to work with the community to develop a new governance and service delivery structure. The ministry would focus on providing family development services rather than general family supports; family development services included those that increased a family's capacity to care for their children. Programs were to be targeted to those in greatest need, eligibility was to be restricted, a new rate structure was to assign levels of funding depending on need, and families would again be "encouraged" to contribute to the costs. Individualized Funding was to be introduced to families for some services, e.g., for children with autism. Children in residential care would, where possible, be shifted from staffed group homes to family foster care.

Overall there was to be a 23 per cent decrease in the MCFD budget. However, Community Living Services were slated for a 17 per cent reduction.[130] The financial targets were to be achieved by 2004-2005.

The Coalition resolved to pursue its governance model with the intention of safeguarding community living services from any further interim policy changes.[131] Some Coalition members saw positive opportunities in that, prior to Christmas of 2001, the proposed cuts for community living would have amounted to 35 per cent, whereas now these had been rolled back by half. As well, there was a time lag before implementation, which left room for lobbying by families.

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[130] The 17 per cent figure is not presented in the Summary but is consistent with the figures shown in February for Adult Community Living Services in British Columbia, Ministry of Children and Family Development (February 2002). *Ministry of Children and Family Development Service Plan 2002/2003 to 2004/2002*, "Summary Expenditure Plan", p. 17.

[131] Community Living Coalition of B.C. "Minutes Jan 18, 02".

VIII. Inception and Work of the Community Living Transition Steering Committee

In response to the MCFD Service Plan, the Coalition proposed that a Joint Transition Working Group be established to lead the policy and program change process. The Working Group was to consist of community members and government officials. The government accepted the proposal and set in place what would subsequently be called the Community Living Transition Steering Committee. This section of the report provides an overview of these developments.

A. Community Proposal of a Joint Transition Working Group

In view of the MCFD *Service Plan*, it was identified at the Coalition's meeting of January 18, 2002 that a transition process needed to begin immediately and that the Coalition should lead it through the creation of a Joint Transition Planning Group that would oversee policy, services, financial and other resources for supports to people with disabilities. The Team was to consist of ten people, 75 per cent of whom were to be community representatives, i.e., 4 family members and self-advocates, one representative from BCACL, two service providers and three government representatives. It was recognized, however, that the numbers may need to be increased to reflect regional representation.[132]

There was also discussion about formalizing the chair, spokespersons, working groups/committees, and meeting schedule of the Coalition.

While there was inconclusive discussion about a range of other issues at that the January 31 meeting (e.g., congregate care, keeping services to children and adults together, the Minister's assertion that the Coalition had "asked" for cutbacks), the Coalition resolved that the community representatives of the

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[132] *Ibid.*

Community Living Coalition Transition Team would be exclusively chosen by the Coalition.[133]

By its next meeting on February 4, 2002 a Coalition website had been established, a communications committee had been established as the first contact for the media, and arrangements were made to have family members, self-advocates and service providers to serve as contacts so that people interested in the work of the Coalition would have someone to contact with whom they would feel comfortable.

The Coalition further formalized its composition at that meeting by requiring that people interested in becoming members be committed to the *Transforming Community Living* document of November 30, 2001 (i.e., the Coalition's "Community Governance Proposal"). While the Coalition would welcome debate, dialogue and questions, members were to support key values and principles that were as yet to be clarified.[134]

Various working groups had been previously established, including Operating Model / Savings / Labour Relations, Communications, Governance. To that was added a committee on Finance and Budgeting. Conflict of Interest Guidelines were discussed. Composition of the Joint Transition Working Group was agreed upon: 9 parents, family members, family representatives or self advocates (at least 2 of which had to be self advocates and 2 from outside the lower mainland); one BCACL representative, three service providers and four Ministry staff. Selection process was deferred to a later meeting. Terms of Reference for the Working Group, which had been developed over the previous few weeks, were approved as circulated.

It was agreed that a delegation would meet with the Minister of MCFD to present the transition team proposal.

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[133] *Ibid.*

[134] Community Living Coalition of B.C. "Minutes Feb 4, 2002".

B. The Issue of Community Representation

At the Coalition's meeting with the Minister of MCFD on February 8, 2002 he expressed concern about whether the Coalition represented a broad cross-section of stakeholders.[135] A draft paper had been developed to address this concern, which the Coalition approved in principle to be taken back to the Minister for further negotiation.

At the February 15 Coalition meeting, the issue of representation was flagged by a representative of Militant Moms on the Move, an advocacy organization active on issues of autism. She indicated that the Coalition was not representative of families, that too many service providers were involved, and, as the rules and vision were predetermined, the Coalition was not truly open to participation.

She also expressed the view that the Coalition was legitimizing the dismantling of Community Living Services by cooperating with the Minister of MCFD and asked for the Coalition to join her organization in requesting a freeze in the ministry's restructuring process and in obtaining community feedback on restructuring proposals. [136] Coalition members responded that, under their proposal, individuals and families were intended to have control of the governance arrangements and that Individualized Funding would be an option for families and individuals.

While Coalition members offered to meet and discuss the concerns of Militant Moms on the Move and other groups, the issue of representation in the Coalition and in community governance persisted well beyond that meeting.

C. Inception and Mandate of the TSC

On March 12, 2002 another discussion took place between the Minister of MCFD and a delegation of the Community Living Coalition about forming a Transition Steering Group that would comprise selected members of the

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[135] Community Living Coalition of B.C. "Minutes Feb 15, 2002".
[136] *Ibid.*

Coalition, government representatives and community representatives who were not then-members of the Coalition. The proposed Steering Group was to recommend to Minister Hogg a transition plan to transfer authority and responsibility to a new governance structure. The Minister agreed in general that such a Transition Steering Group would be established.[137]

Minister Hogg issued the Terms of Reference for the Steering Group (TSG) on April 10, 2002. The terms provided for the Minister to appoint fourteen representatives of the Coalition. Ten were to be people with disabilities and/or family members (at least two of whom were to be self-advocates, two from outside the lower mainland, and two family members of children). There were to be three service providers (at least one of which was to be from outside the lower mainland) and one representative from BCACL. The Minister reserved the right to make eleven additional community-based appointments, comprising family members, self-advocates, service providers (including private contractors) and ministry staff.[138]

The mandate of the TSG was to make recommendations to the Minister, defining the terms for the successful transfer of responsibility for delivery of community living services to a new provincial authority. Recommendations were to encompass finances, staffing and other resources/assets consistent with the ministry's budget and any other necessary elements and processes.

The TSG was to work with ministry staff in developing enabling legislation and regulations to provide the choice of individualized funding and direct funding to families.

The benchmark date (i.e., baseline) for all recommendations about funding and asset determination was December 31, 2001. The work of the TSG was to be completed by September 30, 2002.

The Assistant Deputy Minister of Regional Operations was to be the Ministry co-chair. A member of the Coalition, appointed by the Minister, was to be the community co-chair.

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[137] Community Living Coalition of B.C. "Minutes March 14, 02".

[138] Gordon Hogg, Minister, Ministry of Children and Family Development (April 10, 2002). "Transition Steering Group Letter – Updated Terms of Reference, April 10, 2002".

The TSG was mandated to appoint working groups as necessary, which could consist of TSG members, other ministry staff and other community representatives. The working groups were to report to the TSG.

For its part, MCFD was to support the work of the TSG, provide direction when necessary and receive the recommendations. Ongoing MCFD support was to include advisory, investigative/research, consultative and clerical services, support for self-advocates, reimbursement for members' travel and other expenses, and a Project Manager.

The TSG was to make decisions by majority vote, recording contrary votes at the request of any TSG member.

The Deputy Minister was to consult with, provide updates and receive TSG recommendations on ministry policy or service delivery change.

A Strategic Planning Group was to be established. It was to be responsible for providing information and advice to the TSG and for formulating recommendations for its consideration. This group was to consist of five to eight members agreed upon by the two co-chairs, the Co-chairs themselves and the Project Manager.

D. Areas of Focus and Committee Structure

The group met for the first time on April 24, 2002 and formally called itself the Community Living Transition Steering Committee (CLTSC) from that point onwards. However, members of that committee and other people who took part in interviews and focus groups for the present research generally referred to the work of the Transition Steering Committee, and used the acronym TSC instead of CLTSC. Accordingly, "TSC" is used as the acronym for the Community Living Transition Steering Committee in the remainder of this report, unless the acronym "CLTSC" is quoted directly from documentation.

The TSC met approximately every two weeks from April through August 2002, weekly throughout September and concluded its work on October 22,

2002. Minister Hogg and Deputy Minister Chris Haynes attended some TSC meetings.

The Co-chairs appointed by the Minister were David Driscoll and Elaine Murray. Mr. Driscoll was Executive Director of the VanCity Community Foundation. Ms. Murray was Assistant Deputy Minister, Regional Operations, with the Ministry of Children and Family Development.

General agreement was reached as to task groups on the first meeting (April 24, 2002). The following Work Groups were established at the second meeting (May 16 and 17, 2002):

- Strategic Planning, which consisted of TSC members
- Governance, Service Delivery Management, Policy and Legislation
- Individualized Funding and Planning Options
- Communications
- Accountability and Information Transfer
- Human Resources and Finance
- Children and Families (Joint Children and Youth with Special Needs Directorate)

Committees were to consist of a maximum of 8 members. Additional community members could be invited to participate. Ministry staff providing support to Work Groups would not be counted as committee members.

It was unanimously carried at the May 29 and 30, 2002 meeting that a Work Group would have no separate authority from the TSC, that external membership on a Work Group was not subject to TSC approval but that a given Work Group as a whole must approve any outside membership (i.e., appointments were not to be the sole decision of the Work Group Chair).

It was also unanimously approved that Work Group Chairs who were not members of the Strategic Planning Group would be invited to attend the Strategic Planning Group's meetings as non-voting members.

There were initially two camps at the TSC table. One group was quite suspicious and saw the TSC as the agent of Community Living Coalition and began to caucus quietly. Meanwhile, people at the TSC table who understood themselves to be representatives of the Coalition strategized as well. As work proceeded, the camps reportedly dissolved, although not entirely so.

E. Work Plans

Each Work Group was charged with responsibility for developing its own work plan. Work Group Chairs were asked to sign Memoranda of Agreement committing each group to delivering tasks in the available time.

The overall critical path per the May 29 meeting of the TSC was as follows:

Phase 1	May 29 and 30	• Completion of work plans
Phase 2	June 1 – July 31	• Work on tasks • Draft recommendations to TSC
Phase 3	August	• TSC review of recommendations • Further work on tasks
Phase 4	Mid-September – September 30	• Draft report • Present report to Minister

F. Overall Guiding Principles for the Work of the TSC

At the first meeting of the TSC the Chair expressed the view that Committee members would ideally use a consensus approach to decision making, with majority vote as the default position. The latter was a requirement of the Minister of MCFD.

The position was articulated at next meeting that: "The principles of mutual respect, collaboration, honesty, trust and openness between members is critical to the success of the TSC. The TSC will try to reach a consensus whenever possible."

It was unanimously agreed, on the meeting of May 29 and 30, 2002 that "The TSC is open to receiving presentations/submissions [in writing and through other means from individuals and organizations] only if there is a compelling reason and that this decision is at the call of the Co-Chairs". Perhaps the word "only" was telling. Some people who we interviewed felt that the TSC was well meaning yet insular.

G. Key Issues to Be Addressed

At its inaugural meeting, the TSC identified several key issues that required attention. Some related to services and funding for people with developmental disabilities, specifically the now familiar themes of:

- Funding to address wait lists;
- Recovery of funding transferred to other ministries for supports for people with developmental disabilities;
- Eligibility for services;
- Levels of support for people currently receiving services; and
- Community Care Facility licensing.

Other issues concerned the role and responsibility of the TSC itself, such as:

- The relationship of the TSC to service delivery design;
- Linkages between the TSC and the Interim Joint Policy Directorate for Services to Children with Special Needs;[139] and
- The relationship between the TSC and other steering groups.

Aside from logistical and administrative matters concerning day-to-day operations of the TSC (e.g., committee expenses, resource allocation, consulting fees, etc.) and the substantive work of the Work Groups, several key issues recurred from April through September.

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[139] An Interim Joint Policy Directorate for Services to Children with Special Needs had been established in April 2002 to report to the Minister of MCFD and to the transitional and governance authorities for children and family development, aboriginal services and community living services. Members were responsible to and were to report to the transitional and governance authorities they represented. Services and programs under the responsibility of the Interim Joint Policy Directorate were the Infant Development Program; Supported Child Care; Early Intervention Services (Therapies); School Age Therapy Services; At Home Respite Program; Early Intensive Intervention (for children with Autism Spectrum Disorder under 6 years of age) and the Community Brain Injury Program. The directorate had broad responsibilities for service delivery, policy and funding allocation. It consisted of three government officials and nine community members, three of whom were representatives of community living services based upon the recommendation of the TSC. See http://www.mcf.gov.bc.ca/change/jpd/tor.htm.

An ever-present concern was the budget deficit and the need to achieve cost savings. At the TSC meeting on May 16, the Deputy Minister of MCFD underscored the point that budget targets in the Ministry's three-year service plan were not debatable, must be reflected in the recommendations of the TSC and must be met by the new Provincial Authority. However, the Deputy Minister offered to stop deficit reduction planning and implementation for Community Living Services for fiscal year 2002/03, an offer that the TSC unanimously agreed to accept on May 17. The TSC also agreed at that meeting to reinforce each Work Group's mandate to encourage creative cost savings, guided by the principles that there would be:

1) No reduction in service quality;
2) No changes in eligibility;
3) Increased system capacity to respond to new service pressures; and
4) Elimination of infrastructure barriers.

The TSC slated the issue of inter-ministerial linkages for future discussion.

The TSC subsequently appealed at its meeting of May 30 for MCFD regional staff and service providers to work together to realize savings, based on the following principles:

1) Changes would be mutually identified by individuals, their advocates or family, service providers and MCFD;
2) All-party agreement to implementation of proposed changes;
3) Equal or improved service quality;
4) No change to eligibility; and
5) Maintenance of the safety of individuals with developmental disabilities.

Given that savings were to be achieved – a point that did not seem debatable given the Ministry's position – the TSC pressed for recovery and retention of savings to address wait lists and other service short falls. The TSC resolved at its meeting of May 30, 2002 to ask the Minister of MCFD to approve the carry over of any savings gained through operating efficiencies, innovation and creative change to the next budget year, for the benefit of the new Community Living Provincial Authority. The TSC envisioned that this Authority would eventually have responsibility for community governance, service delivery, management of funding, service standards, and so on.[140]

It was also noted at the meeting of June 14 that the participation and support of service providers in new governance and service arrangements would be conditional on the commitment of the Ministers of MCFD, Finance and Treasury Board to carry forward any surplus into next fiscal year.

The TSC worked over the summer under the impression that such savings could be carried over into next fiscal year and would be credited against funding reductions to become effective in the new fiscal period. To that end, the TSC initiated a savings plan (June 14), to be developed in collaboration with MCFD, to assist people on wait lists within existing funding parameters rather than through additional funding. It also approved the creation of a joint committee comprising Ministry staff and service providers to begin implementation of such a plan. At its meeting of July 25, the TSC unanimously approved a draft of its Cost Saving Plan, which was intended for implementation by the successor Community Living Services Transition Authority in collaboration with MCFD, with communication to families, service providers and Ministry staff in September 2002. The TSC intended that the plan would become fully operational in October 2002.

On June 26 it was reported that The Minister had committed to carrying forward any cost savings – provided that a new provincial authority was in place before April 1, 2003. Failure to meet that condition would mean that any savings would be lost; Treasury Board approval for this commitment was pending.

Understandably, then, proposed legislation for the creation of governance structures was discussed at several points, e.g., at the meetings of June 14, June 30 and again on September 6.

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[140] The TSC had hoped to generate savings in fiscal year 2002-03 that would reduce by one half the budget cuts of $80 million to the community living budget slated for that and the next fiscal year. See Ministry of Children and Family Development, Community Living Transition Steering Committee (September 6, 2002). "Minutes".

Meanwhile over the summer, the TSC also considered impacts of various pieces of new legislation, regulations and policy on people with developmental disabilities and their families. This included Bill 27, *Employment And Assistance for Persons with Disabilities Act,* which authorized the Minister of Human resources to reduce or suspend income support to people with disabilities not participating in an employment program specified under the legislation. At its meeting of May 29 the TSC called for arrangements to ensure that people with developmental disabilities, their families and advocates would have significant input and would be consulted in the drafting of the regulations.

The tax implications of direct payments to families were discussed at the meetings of June 14 and 30, then again on July 12 and August 23.

Issues of the transition of young people from children's to adults' services were discussed on June 30.

Safeguards for people in the current service system were discussed on June 30.

The issue of communication with families and organizations not directly involved with the change process was discussed on July 12 and 25 and again on September 6 and 14. On September 14 it was reported that the TSC was dealing with an increasing volume of inquiries from the public. It was reported at the meeting on September 19 that TSC staff were fielding rising numbers of concerns by parents about the future of their sons and daughters with developmental disabilities. It was recognized at that meeting that, during negotiations between the TSC and the Ministry, continuity of communications would be essential because rumour and mistrust were likely to increase when ambiguity was high. From July 15 to September 27, twenty-four information sessions were conducted in eighteen communities that involved more than 1,700 people. Interactive video conferences were also conducted in 23 communities from September 18 to October 17, involving TSC members and about 450 family members, self advocates, service providers and MCFD staff across the province.[141]

Throughout the deliberations of the TSC, the status and positioning of individual-planning functions in new governance arrangements was a key issue. Challenges were to ensure that such support for individual planning would:

- Be autonomous from funders and services;
- Be available at the local level to people who need/request it;
- Accord status to the personal networks of individuals in the planning process;
- Facilitate linkages between individuals with disabilities and sources of funding, traditional and new models of support, and a robust "social economy";

The planning function also had to be fiscally sustainable.[142]

H. Unexpected Turn of Events and the TSC Response

During the course of its work, the TSC had been operating on the assumption that the successor Community Living Services Transition Authority would have overall responsibility for service delivery in the community living sector. The TSC had also been operating on the belief that any savings generated in fiscal 2002/03 would be carried forward into fiscal 2003/04 to offset funding cuts that were slated to come into effect, then.

However, it was reported in the minutes of the TSC meeting of September 6, 2002 that draft legislation did not provide for the service delivery capability of any of the interim Authorities that were slated to come on stream (i.e., for children, Aboriginal persons or for community living). Further, Treasury Board staff had recently indicated that provincial auditing policy precluded the transfer of unused service funds from one fiscal year to following years.

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[141] Community Living Transition Steering Committee (October 2002). *A New Vision for Community Living…a vision of choice and change.* Vancouver: Author, pp. 285-287

[142] Ibid., pp 202-203; 210.

It was in this context on September 6 that the TSC discussed MCFD's proposal that service delivery be "co-managed" between the Ministry and the new Authority.

Concerns of the TSC were that the notion of "co-management" was undefined. Further, the TSC felt that the interim Authority's lack of service delivery mandate would impede its achievement before April 1, 2003 of the service transformations and associated savings that had been envisioned and discussed.

Concerning the Treasury Board determination that prevented carrying forward any savings into other fiscal years, the implications were "very serious and of great concern", resulting in "shock and dismay" and a "lengthy and passionate discussion" at the TSC table.

Following an in-camera session, there was unanimous TSC support for a motion to inform the Minister that, "under these circumstances,[143] it will be impossible to protect the safety and security of vulnerable people currently being served, and to ensure a successful transformation to a Community Living Authority".

While these developments were clearly not "good news" for the TSC, following other in-camera sessions in September, TSC members reiterated their commitment to their mandate, outlined to the Minister their concerns (September 14) and identified members (September 19) to work with the Ministry on its Budget plan for presentation to Treasury Board by October 31 of that year.

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[143] I.e., the interim Authority's lack of mandate in the area of service delivery and the inability to carry forward savings from one fiscal period to the next.

IX. Report of the TSC

The Final Report of the TSC was completed at the end of October 2002. Entitled *A New Vision for Community Living…a vision of choice and change*, it is a massive document of 427 pages. This section of the present report provides an overview of that document.

A. Guiding Principles and Values

Guiding principles of the TSC's vision as laid out in its report were:

- Full citizenship of people with disabilities in their communities;
- Honour for and encouragement of individual contributions;
- Trust in the capacity of individuals and families to meet the challenges they face and to develop their own support system;
- Individual and family capacity development and resiliency so they can live more independent of government services;
- Respect for the decisions of individuals and families;
- Building the capacity of communities to recognize and value the contribution of people with disabilities; and
- Availability of support for individuals and families when needed.

The proposed new system laid out in the document would:

- Focus on individual and family support, with independent planning as a core feature;
- Afford greater choice and respect for choices;
- Ensure life long supports to assist individuals and families facing challenging life transitions;
- Restructure the role of government in its service-provision relationship with the community;

- Reduce the size and presence of government and the complexity of regulation; and
- Develop communities with a view to the capacity that is already present, there.[144]

B. Key Themes and Objectives of the Report

Key themes and objectives at the centre of the report include community-based governance, citizenship and choice, accountability and transparency, safety and well-being. As well, the report explored some of the organizational and financial implications of the proposed new system.

1. Community-Based Governance

Community-based governance was to involve the following:

- Establishment of a new community governance arrangement that would ensure government responsibility for appropriate funding for services but that would transfer responsibility for management and service delivery to the community.
- Creation of a new Authority with a legislated base to undertake these responsibilities.
- Government appointment of the Authority's Board of Directors, stemming from community-based nominations with a majority of Board members being self-advocates or family members of a child with a disability.
- Adherence of the new Authority to principles and policies to ensure the safety and well-being of the people supported, maximizing and developing community capacity in the process.
- Provision of independent planning and support for adults, children and their families through a planning support Commission consisting of five persons.

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[144] *Ibid.*, pp. 26-27.

- Appointment of the planning Commission by the new Authority's Board of Directors, based on community nominations and consisting of self-advocates or family members of a person with a disability.
- Community presence of the planning Commission through 12 to 15 local Community Planning Support Centres.

2. Citizenship and Choice

Citizenship and choice meant the following:

- Provision, under the new Authority, of the supports needed for people to live satisfying lives in the community and to enhance their contributions as citizens.
- Establishment of individualized funding under the new Authority for eligible people and their families, which was to address the needs of the child and the family in the event that the funding is for children.
- Freedom of recipients of individualized funding to seek access to globally funded (e.g., already existing) programs and to explore new alternatives.
- Mandate of the new planning Commission to establish and deliver planning support to all adults, children and families who wish it.
- Responsibility of the new Authority for life long support for eligible people and their families.
- Encouragement by the new Authority of individual and family contributions to the support and service system, with the new Authority seeking recognition of these contributions in the federal and provincial tax system.
- Legislation, regulation and policy to enable the Authority to permit parents or siblings to be compensated as caregivers where warranted.

3. Accountability and Transparency

The TSC defined accountability and transparency to mean:

- High standards of financial management, reporting, accountability and transparency for the new Authority and Commission in relation to government, the legislature and the public.
- High standards for the new Authority and Commission in terms of operational performance monitoring, measurement and reporting to the people supported, government, the legislature and to the general public.
- Operation of the new Authority within the financial parameters set by government, including that the Authority not operate at a deficit without the approval of the Minister responsible or borrow funds without approval of the Minister of Finance.
- Determination by the new Authority of outcomes to be achieved for individuals and families and outcomes to be achieved in terms of service delivery standards.
- Establishment by the new Authority of efficient and effective mechanisms for problem-solving and dispute resolution on issues involving the Authority, individuals and families served, government, service providers, and so on.
- Public meetings of the new Authority's and Commission's Boards of Directors.

4. Safety and Well-Being

Safety and well-being were to be secured by the following:

- Establishment and maintenance by the new Authority of quality assurance mechanisms to monitor the safety, security, care and quality of life of people supported by community services or receiving individualized funding.
- Maintenance and protection of current funding levels for community living services delivered by the Ministry of Health Services and Regional Health Authorities; transfer of funding to the new Authority for the mental health program for community living.
- Maintenance of funding levels for children with special needs in care, return to the new Authority of all mental health funds for people with developmental

disabilities under the Ministry of Health Services; maintenance of Regional Health Authorities' level of service for community living.[145]

5. Organizational and Financial Implications

The TSC's report provided a structural overview of the proposed governance arrangements and touched upon a range of financial considerations. The latter included expenditure challenges during the transition to new arrangements, among which would be one-time costs that had to be addressed regardless of then-present budgetary provisions.[146]

Through October 2002, five TSC members worked with five MCFD officials in a Joint Budget Working Group and arrived at the common position that between $45 and $50 million would be needed to address such transition costs.[147] That work paid off; $47 million for these costs were included in the budget for 2002-2003.[148]

The TSC's report also addressed the re-allocation of the present human resource complement at MCFD and other human resource implications, limiting the future costs to government and to the new Authority through innovation and increased productivity, and recouping revenue through the sale of selected assets.[149]

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[145] *Ibid.*, pp 50-60.

[146] One-time costs that needed to be addressed are articulated at greater length than in the TSC report in British Columbia, Community Living Co-Management Committee (Undated). *Update on Service Strategies for Community Living 2003/2004.* Victoria: Author. Such costs would be incurred for additional staffing and training/retraining, mentoring and facilitation needed for anticipated changes; notice period on cancellation of existing service contracts with agencies; support for collaborative, multi-agency planning and for sole-agency planning; and disability-specific renovations and alterations to some family and group homes.

[147] The Final Report of the TSC's Human Resource and Finance Planning Committee (in the Appendices of the TSC report) brought forward the point that the Joint Budget Working Group "no longer believes that meeting the Ministry service plan requirements for budget reductions are possible while, at the same time, also ensuring a successful transition to the new Authority. However, we remain committed to increasing the effective use of existing funds." See also Doug Woollard and Deanna Kratzenberg (Tuesday, October 22nd, 2002). "Memorandum to All TSC members - Update on Joint Budget Working Group". This memo is included as Appendix 1 in British Columbia, Community Living Co-Management Committee (Undated). *Update on Service Strategies for Community Living 2003/2004.* Victoria: Author.

[148] MCFD Evaluation Committee (November 2002). *Furthering the Vision for Community Living: Next Steps – Evaluation Committee Response to the Community Living Transition Steering Committee Report.* Victoria: Author.

6. Expert Input

The TSC invited the following people to respond to a draft of the report prior to its completion:

- Dr. Jeffrey Roy, Dr. Luc Juillet and Denis Desautels, University of Ottawa – Centre for Governance;
- Denis Bell – Chief Executive Officer, Regional Authority, Persons with Developmental Disabilities, Province of Alberta;
- Dr. John O'Brien – Responsive Systems Associates, Research and Training Center on Community Living, Center on Human Policy, Syracuse University, New York;
- Richard Crocker, Regional Chief Executive Officer, New Hampshire Services to People with Developmental Disabilities;
- Eddie Bartnik – Director, Disability Services Commission, Western Australia; and
- Dr. Michael Kendrick – Kendrick Consulting International, Formerly Assistant Commissioner – Massachusetts Department of Mental Retardation.

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[149] e.g., group homes of people who opt to move elsewhere; the sale of the Woodlands property.

X. Selected Critiques of the TSC's Report

It is beyond the scope of the present research to detail all reactions to the TSC's final report, 32 of which were posted at a MCFD website.[150] However, three critiques are particularly noteworthy and are explored in this section of the present report.

First, the Minister of MCFD had established an Evaluation Committee to apply three critical tests, namely, whether the mandate to create community-based governance had been met, whether any of the recommendations exceeded the statutory powers of the Minister or otherwise precluded him from acting on the recommendations, and whether the TSC had applied their knowledge and expertise to make the implementation as good as possible. Second, the BC Government and Service Employees' Union (BCGEU) weighed in with a formal response to the report. Third, Family Partners also provided a response. The latter group included one person who had been a member of the TSC and who broke ranks towards the end of the process over what she felt were an excessively bureaucratic and redundant planning functions. The group also included Militant Moms on the Move, and people involved with various service organizations and family/parent support groups.

A. MCFD Evaluation Committee Response

The MCFD Evaluation Committee responded to each of the 59 recommendations contained in the TSC report and provided several additional comments. The Evaluation Committee supported ten of the recommendations, rejected thirteen and gave qualified support for the remainder. In its conclusion the Evaluation Committee said, that it "supports the general direction of the CLTSC vision. Where the Evaluation Committee has differed from the CLTSC it is more related to the means of getting to the destination, rather than the destination itself."[151]

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[150] Available at http://www.mcf.gov.bc.ca/change/cltsc_comments.htm. The Ministry received comments until March 31, 2003.

Overall the Evaluation Committee found that the TSC had applied their knowledge and experience to make the implementation as good as it could be, given that the TSC was operating at a preliminary stage of transition to a new Authority. However, the Committee indicated that the report did not include enough information for it to determine what delivery outcomes were likely under the proposed governance model and that the Minister's authority had been exceeded on budgetary matters, on matters that pertained to another ministry's responsibilities and on cross-ministry issues. The Committee indicated that that the TSC's report provided little information on how community members were to be engaged in expanding the choices of individuals with disabilities and little information on how the financing arrangements would lead to decreased dependency on government. The Committee had concerns about the Planning Commission in that it would likely increase costs, would be the public face of the Authority while the Authority itself would have no direct community presence, and would develop service plans without reference to the Authority's budget. The Evaluation Committee also took issue with several of the TSC's ideas concerning the composition and nomination of the Authority's Board of Directors. Many of the Evaluation Committee's responses were forward thinking in the sense that they focused less on the TSC report and looked more at "next steps" that the new Authority would need to address.[152]

B. BCGEU Response

While generally supportive of the basic principles of the TSC report, the BCGEU characterized the report as "long on philosophy, but short on practical detail". It expressed concern about further increasing the community's responsibilities in the context of budget and service cuts and the potential for government "offloading" of responsibilities; the TSC had expressed its own concerns in this regard as well. The BCGEU expressed concern about community presence in rural communities when services were to be shifted from broadly available government offices to only 12 or 15 planning centres. Other BCGEU concerns revolved around the adequacy of pay for workers in the sector under Individualized Funding and under the regime of budget cuts, and the protection of government employees' jobs under any transfer to a new Authority.[153]

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[151] MCFD Evaluation Committee (November 2002). *Furthering the Vision for Community Living: Next Steps – Evaluation Committee Response to the Community Living Transition Steering Committee Report.* Victoria: Author, p. 57.
[152] *Ibid.*

C. Response by Family Partners

In response to the TSC report, Family Partners indicated that they "overwhelmingly support the overarching principles that the health and safety of individuals must be paramount and that all change must be based in choice for individuals and families". However, they had a number of concerns and requested a delay in implementation until issues needing clarification were "fleshed out".

Concerns revolved around how budget targets were to be met and the implications of massive restructuring in the context of budget cuts. They also indicated that the report did not address the needs of small, rural and remote communities, and would take services further away from rather than closer to such communities. They pointed out that the report did not speak to the needs of people with developmental disabilities whose families were not in the picture to provide support and did not adequately address the majority of families who did not see Individualized Funding as an option for themselves. Nor did the report provide practical detail on how the needs of people who were on wait lists or who were under-served were to be addressed. Family Partners indicated that broad community support for the report could not be assumed and that the proposed nomination and appointment process for the new Authority would perpetuate the continuance of people already at the TSC table.

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[153] "A response from the British Columbia Government and Service Employees' Union to the Community Living Transition Steering Committee Final Report and MCFD Evaluation Committee Evaluation of the Report." Available at http://www.mcf.gov.bc.ca/change/consultations/CLA/bcgeu_jan3.htm.

Family Partners also expressed concern about the proposed transfer of mental health teams to the new Authority, the fragmentation of children and youth across several bureaucracies, the lack of detail on the accountability of the new Authority to families and communities, on how to maintain the safety and security of individuals with disabilities during the transition and into the longer term, and on how to ensure that effective staffed service models would survive the restructuring process.[154]

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[154] Letter from Family Partners to Hon. Gordon Hogg, March 3, 3003. Available at http://www.mcf.gov.bc.ca/change/consultations/CLA/family_partners_mar4.htm.

XI. Interim Authority for Community Living British Columbia

On October 21, 2002 – about the same time that the TSC submitted its final report to the Minister of MCFD – the *Community Services Interim Authorities Act* passed First Reading in the Legislative Assembly (October 21, 2002). Ten days later it was given Royal Assent and enacted into law.

On November 13, 2002, the Minister of MCFD appointed Board members and entered into a Memorandum of Understanding (MOU) with the Chair of the Board of the new Interim Authority for Community Living

The first Board of Directors was made up of thirteen family members and self advocates who had sat on the TSC. Eleven further people were appointed in January 2003 after a province-wide nomination process that took place in the November 2002.

Eighteen of the Directors of the January Board were parents of children with a developmental disability or autism spectrum disorder and three were self-advocates. The Chair of the Board of Directors was David Driscoll; the Deputy Chair was Susan Whittaker.

As set out in the MOU, the Interim Authority was to continue building on the work of the TSC at the discretion of the Minister. The MOU confirmed the guiding principles for the joint work of the Interim Authority and the Ministry, defined a structure for co-management of community living services by the Interim Authority and the Ministry, described the powers, duties and responsibilities of the Interim Authority and spelled out various other details on information sharing, communication, and relations with other Interim Authorities and government / quasi-public bodies. The MOU confirmed the continuation of a

Joint Policy Directorate with responsibilities for services to children with disabilities.[155]

It is beyond the scope of the present research to document the work and issues facing the Interim Authority and its responses to those challenges. Many of the challenges with which the TSC had begun to wrestle, however, had to be addressed by the Interim Authority through concrete policy and operational detail as it prepared for the final transition of community living services to a fully constituted Authority for Community Living, intended to occur in the spring of 2004.

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[155] British Columbia (November 13, 2002). *Memorandum Of Understanding between The Interim Authority for Community Living British Columbia and The Ministry of Children and Family Development.* Victoria: Author.

XII. Limitations and Strengths of the TSC Process and Further Considerations

This section of the report provides an overview of some of the key limitations of the TSC process, some of its strengths and some further considerations on lessons to be drawn from the process.

A. Some Limitations

Some limitations of the TSC and its work included the perception that the TSC's work was rushed, that a radical approach to service reform was adopted in opposition to an incremental approach, that the TSC and Community Living Coalition enjoyed limited success in bringing about and maintaining the broader community and government "buy in" that was sought, that more detail was needed on important technical issues and that the community's expectations were unrealistically raised in the context of severe spending and service cuts.

1. Rushed Agendas

By most accounts, the pace of the TSC's work was hectic throughout the summer of 2002.

Some interview respondents indicated that the TSC was unnecessarily limited by its sense that, if legislation were not in place for an Interim Authority by the fall, all would be lost. One person indicated that government presented a timetable that was unrealistic. This respondent felt that the Ministry would probably have been happy to place a focus on legislation in the spring of 2003 and that the leadership of the TSC should have targeted the spring from the outset. Failure to do this created a crisis orientation for the TSC's work, resulting in the impression that "everything had to be taken care of by tomorrow".

It also left the impression to some that the TSC was "herding" others. It was as if the TSC was saying, in the words of one interview respondent, "We haven't got time to bring you on board. Just trust us."

2. Radicalism *Versus* Incrementalism

In the interviews and in documents that were reviewed for the research there was a recurring tension between incrementalism and radicalism. Some government officials and some in the community who were interviewed tended to favour incremental changes and improvements to the community living system. For instance, some families were happy with the *status quo* and wanted little or no change in their sons or daughters' situations. Some others were not entirely happy with present state of things, but didn't want to completely re-invent the system, either.[156] Still others saw a need for a more radical approach in the interests of meeting goals of individual and family choice, personal control, greater fairness, portability and flexibility, sustainability and so on.

At some level, both approaches were probably needed, i.e., an approach that would conserve and build on what was in place and valued, while opening the door wider to further innovation, self-determination, flexibility and other values. Such a merging of incremental and radical approaches would have taken a longer time to bring about than was available to the TSC in its lifespan. Those who favoured a slower moving approach tended to feel alienated by the work of the TSC and by the broader system reform process.

3. Securing and Maintaining "Buy In"

The community and government "buy in" to the work of the Coalition and TSC was somewhat tenuous owing to fractures that emerged at the TSC table itself, what some characterized as the insularity of the TSC, a community outreach strategy that ideally would have been more robust, a perceived weakening of government confidence and the ambivalent leadership role of families.

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[156] See, for instance, Bulkley Valley Community Living Council (November 30, 2001). *Response to the Ministry of Children and Family Development's Core Services Review.*

a. Fractures at the TSC Table

Several interview and focus group respondents felt that there was greater solidarity in the community living sector as a result of the community mobilization that led up to the creation of the TSC and that persisted through the TSC's work. That view was not universally shared, however. Two people left the TSC over differences of opinion as to the directions and recommendations of the Committee. At issue were the pace of system reform and a range of other details that are discussed below in the section on Technical Matters.

b. Insularity

There was a sense in a few interviews that the TSC exuded a "you're with us or against us" attitude and a stridency of approach that was difficult for some people to bear. In much the same way, some people who we interviewed in the fall and winter of 2003 saw the same kind of insularity in the Interim Authority that they saw in the TSC.

As well, some MCFD staff – not necessarily those at the TSC table – reportedly felt pushed aside and unvalued by the TSC, despite the statements of valuing that are contained in the TSC's final report.

Not all perspectives *were* represented at the TSC table. The people appointed to the TSC were mainly from the Community Living Coalition – quite intentionally so. Said one respondent, "There was a problem with Coalition having control, and saying they represented everyone, when it really wasn't the case… People don't want to crash this or see it fail, but they do want access, input. They want to ask questions, have issues and questions considered in fair and open way, but this isn't the process."

c. Community Outreach Strategy

Some respondents spoke about how, despite the flurry of information sessions in the summer of 2002 and efforts to communicate through the Internet, the TSC was not highly successful in bringing other people into the picture; there was a good deal of confusion and apprehension in the community as the TSC wrapped up its work, confusion and apprehension that persisted during the work of the Interim Authority.

To some extent, the TSC was not in a position to answer the community's questions in a definitive way because the operational phase of the transition was not underway when the TSC was doing its work, and the TSC's thinking was taking place at a higher conceptual level than at a detailed practical and operational level. As well, the TSC was already dealing with a packed agenda simply trying to meet the deadline for submission of its report to the Minister of MCFD while also attempting to respond to other legislative and policy developments.

Despite what may have been plausible reasons for the lack of more community outreach by the TSC, the fears and concerns of families had been raised and, from their perspective, not much seemed to be done to allay those fears and concerns – not, at least, until the latter month or so of the TSC's work.

One person characterized the TSC's (and later, the Interim Authority's) communication approach, which was largely website-based, as "hi-tech, low touch". This person pointed out that having a family member with a disability is a "high touch issue" requiring a face-to-face, interactive approach to communication.

The general approach to community consultations that was undertaken probably needed some re-thinking. We heard from several interview respondents that they perceived the outreach and communication process to be one where the TSC – and later the Interim Authority – went out and *talked to* the community rather than went out and *listened to* the community.

Partly as a result of the approach to outreach, some of the community momentum that was generated through the Community Living Coalition dissipated after the TSC finished its work. Said one person who was interviewed who echoed comments of several other research participants, "Once the Interim Authority was established, the TSC went home. Actual community-based activities withered. Coalition meetings were not as well attended. This was a big loss. We were not 'not tending our garden' – [it is as if] other people were taking care of things."

d. Keeping Government Onside

Prior to and early on in the TSC process, several people at the TSC table had personal connections with government at the political and bureaucratic levels. There was a perception among a few interview respondents that some of these relationships were not as diligently cultivated and that people inside government were not kept as well informed during the TSC's work.[157] As the TSC's work unfolded, resistance within some government quarters increased, which the TSC underestimated and did not fully appreciate until government began to "push back". [158]

On several occasions, e.g., in discussions with government officials about keeping services for children and adults together, the TSC used the "deal breaker" strategy. That is, government was presented with the option that it would either go along with the TSC or that the TSC would step away from the table.[159] This led to perceptions among some in government that the TSC had a penchant for playing "hardball" rather than for negotiating, which was not a favourable perception.

Further, issues around budgeting and the TSC's inability to deliver a package within the original funding parameters set by government eroded the confidence of some government officials in the TSC and subsequently in the Interim Authority.

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[157] Some respondents conjectured that perhaps the people at the TSC table who were on friendly terms with government officials felt that they had to be more circumspect now that they were involved in a process of major system redesign.

[158] Reportedly, there was resentment within MCFD about how things had gone on the Community Living side compared with Child and Family Services. Internally within MCFD, staff were saying that "it's a mess on the family side" and that Community Living was "getting off easy" in terms of cuts. Some within government perceived this situation as unfair.

[159] Later, the Interim Authority used this strategy as well.

e. Leadership Role of Families

While family members comprised a significant contingent within the Coalition and the TSC, and had significant say in both the work of the Coalition and TSC, not everyone believed that the TSC was "parent led", including some family members who were interviewed and some senior government officials. This raised questions in some people's minds about the degree to which the work of the TSC represented the aspirations of families of people with developmental disabilities broadly speaking.

The generation of families involved at the TSC table was also problematic. Some younger family members who were interviewed did perceive that families were very much at the helm in the TSC. However, the younger family members were concerned that decisions about the futures of their sons, daughters and siblings would be determined by an older generation of people who were not necessarily on the same "wave length" when it came to aspirations, values and preferred service approaches.

4. Technical Matters

Technical issues that were flagged in the interviews included the perceived lack of operational expertise of the TSC taken as a whole, issues of funding, the separation of planning and funding functions, principles for ensuring fairness in resource allocation, results indicators and the need for differentiated approaches for urban and rural communities.

a. Operational Depth

Several interview respondents commented on what they perceived to be the limited operational and administrative depth of people at the TSC table. Acknowledging that community-based advocates rather than professional directors/administrators had major say at the TSC table, some interview respondents questioned whether there was enough involvement by other knowledgeable people from the community living sector (e.g., experienced service providers).

b. Confusion about Levels and Approaches to Funding

The criticism was made that people involved in the TSC felt that they could do more and better for less money, but without being too clear about how much less money. The impression was left that the TSC wanted to serve everyone with the same dollars, when those dollars were already insufficient to meet pent up demand for supports.

Some service providers found it difficult to undertake voluntary cost cutting because they had already taken on new people to serve before the TSC process was initiated. These providers wanted – and did not get – recognition that their efforts were equivalent to cost cutting.

As well, there was confusion about Individualized Funding: Was this about a flat rate? A three or four level funding scheme? Was funding to be determined and adjusted (i.e., increased) in relation to need? While the overall gist of the TSC's work was clearly in the direction of the latter approach, this was not widely understood.

What complicated matters was that significant resistance had emerged within a relatively small but vocal group who thought that Individualized Funding was going to be, in the words of one respondent, "shoved down everyone's throat". The Coalition was trying to be clear that Individualized Funding was to be an option, and that those who were happy with what they were getting would continue with their present arrangements; the TSC document framed Individualized Funding as an option, too. However, this message didn't "stick". One respondent said, "People had to fight for Individualized Funding to be framed as an option. It wasn't there in the beginning."

As well, the TSC's report did not spell out the technical details about how, at an operational level, Individualized Funding and conventional agency funding would be mixed. How were agency transfers to be "unbundled" and individualized for the people served? In the event that one person were to leave a group home for a more independent living situation, the group home would have to operate short of funds until another suitable person could be found to live with the remaining people living, there. In the interim, how, systemically speaking, would the funding shortfall be addressed for the people remaining in the group home? Such details were not at all clear to several people who were interviewed.

c. Disagreements Over Separation of Planning and Funding Functions

There were arguments at the TSC table over whether and why responsibilities for planning should be separated from responsibilities for funding.

Some members held the view that there was the potential for and likelihood of significant conflict of interest where the authority responsible for decisions on funding also has responsibility for helping individuals to identify and plan for the services needed in the community.[160] Accordingly, some kind of 'firewall' was needed between these functions, which would result in structural tensions between functions.

Some other TSC members, however, either did not understand the rationale for, or could not accept the idea that, such a separation of functions was desirable or necessary. The idea seemed to fly in the face of the need for collaborative approaches and cost efficiencies.

While in its final report the TSC agreed to a separation of these functions, some members came to that point of view late in the process and some continued to favour an integration and coordination of these functions within a single administrative structure.

A further concern that played into the discussions was that the TSC's proposed local centres for planning would be fewer and further away from smaller communities than the more widespread government offices and MCFD social workers. There was a perceived risk that planning functions delivered through the proposed centres would be less available and less responsive to people in smaller and remote communities.

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[160] These concerns can be traced back to learnings based on the early pioneering work of the Community Living Society, which had sought to establish the planning function on an entirely different policy and program footing than decision-making about funding.

Based on interviews conducted for this research, the separation of arrangements for planning and funding was reportedly a very difficult issue for the TSC to work through,[161] one that eventually saw two TSC members break ranks with the remaining members.

d. Principles of Fairness for Resource Allocation

The Evaluation Committee that commented on the TSC's report indicated that issues of equity had not really been addressed. The issue surfaced in the interviews as well: How to ensure that fairness is achieved in resource allocation? Who is to benefit? How much is to be allocated and on what basis?

It was pointed out that principles or guidelines were needed to set reasonable boundaries for resource allocation. These guidelines could be used by families in thinking through reasonable, fiscally sustainable parameters for matching service needs and available resources. The TSC's work did not tackle this thorny issue.

e. Results Indicators

The general principle was enunciated by the TSC that results indicators were needed on two levels: outcomes for individuals (e.g., self-determination, achievement of life goals, quality of life, etc.) and outcomes or standards for services. While it was perhaps unreasonable to expect that the TSC would have been able to provide details on results measurement in the short time available to it, the need for such details persisted. Asked one respondent, "How will you know if and when you've hit your target?"

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[161] See also, for example, British Columbia, Ministry of Children and Family Development, Community Living Transition Steering Committee (September 26 and 27, 2002). "Minutes" of the September 26 meeting.

f. Urban / Rural Differentiation

In some parts of the province, community members were in effect saying of the TSC's vision, "This isn't really our agenda." This seemed to be particularly the case in smaller and rural communities. That viewpoint was not well heard by the TSC and options more suitable to those communities were not explored in as much depth as would ideally have been the case.

As well, the sentiment was not as strong in some communities as in others for families to get control of the system and Individualized Funding. While we had no way of independently verifying the assertion, people were reportedly quite happy with present arrangements in many communities. Some people who were interviewed felt that the TSC should have explored regionalized approaches, allowing for diverse perspectives and options on support issues.

5. Great Expectations and the Perception of Compromise

The point was made in the interviews that there was a persisting gap between, on the one hand, the resources that were actually available to address needs in the community living sector and, on the other, the hopes and expectations that the Community Living Coalition and the TSC generated. Respondents wondered about the wisdom of raising expectations that were unlikely to be met.

Expectations were raised and system redesign efforts rolled forward in the context of major funding cuts. To some, the government did not seem to be asking the Coalition or the TSC for advice about how government could save money, but simply required that 20 per cent be cut in a service envelope where many people were being underserved or not served at all. Said one respondent, "Power was handed to the TSC and the subsequent group[162] to hand in a 20 per cent cut in exchange for control of community living. This was the trade-off."

While the TSC was able to stave off some of the looming cuts, the committee wasn't entirely successful in convincing the government that the TSC's work and follow up had the potential to make a major positive difference and should not be undertaken in context of cost cutting.

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[162] I.e., the Interim Authority for Community Living British Columbia.

The two agendas – saving money and making things better – got intertwined and confused. Decisions that were based on government's resolve to cut costs were blamed on the community living movement.[163]

B. Some Strengths

While the TSC process had its limitations, it also had some notable strengths. The TSC built upon the efforts of earlier parent activists, conducted a committee process that was generally amicable and productive overall, cushioned some of the negative effects of budget cuts, took a realistic and pragmatic approach in which it sought to work productively with rather than antagonistically against government, maintained the vision that was the TSC's reason for being, produced a report for which there was broad level support in terms of the analysis of the issues to be addressed and the overall direction and principles for system reform, and brought about the creation of an Interim Authority for community living that consisted mainly of families and self-advocates.

1. Building Upon Parent Activism

Parent activism, while perhaps not the sole driver of the TSC's work, was definitely a major factor behind the creation of the community living services system, and in persuading the government to close the province's institutions and redirect resources from institutions to the community. Parent activism also played a major role in the planting of key ideas that came to the foreground in the 1990s.

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[163] The Premier and Minister of Finance had determined that they wanted to spend less money, not the same amount for greater effect.

The TSC built on that earlier work, which was grounded in principles of the dignity and value of all people regardless of severity of disability, individual empowerment and self-determination, individualized approaches that afford choice and flexibility, system responsiveness, social inclusion and ensuring basic safety and security while respecting the dignity of risk. The TSC also built upon the notions of Individualized Funding and an autonomous planning function as two system tools for realizing such principles and values. Again, families essentially invented these system ideas in the late 1970's and early 1980s.

2. Good and Productive Process Overall

Generally, people who took part in the research provided favourable reports about the TSC, the committees and the work of the committees. People at the TSC table reportedly had some initial difficulties working with one another. However, TSC members came to mutually respect one another's commitment and found ways of working effectively together, despite differences of outlook and opinion on some issues.

Given that the TSC's final report is hundreds of pages in length, and that the bulk of the work took place from June through September of 2002, it is not an overstatement to say that a great deal of work was accomplished in a very tight time frame.

As well, people who were involved with the TSC were involved with the Community Living Coalition, which had its own meetings that ran parallel to those of the TSC. The work took place over the summer months when people typically prefer to be on vacation instead of going to meetings and doing committee work. As well, most TSC members had regular day jobs in addition to their committee work.

Overview of the meeting schedules of the TSC and Community Living Coalition , April – October 2002

Apr-02

02 - CLC Meeting
10 - CLC Meeting
22 - CLC Meeting
24 - First Transition Steering Group Meeting

May-02

08 - CLC Meeting
16, 17 - TSC Meeting
29, 30 - TSC Meeting
31 - CLC Meeting

Jun-02

13,14 TSC Meeting
26,27 TSC Meeting
28 CLC Meeting

Jul-02

11, 12 - TSC Meeting
16 - CLC Meeting
24, 25 - TSC Meeting
26 - CLC Meeting

Aug-02

8, 9 - TSC Meeting
8th - CLC Meeting
21, 22 - TSC Working Groups
23 - TSC Meeting
29 - CLC Meeting - 9am

Sep-02

11 - CLC Meeting
25 - CLC Meeting
26,27 - Last TSC Meetings before Final Report
30 - TSC Report to the Minister

Oct-02

Community Living Month
10 - CLC Meeting
21 - CLC Meeting
21 - Bill 65 - First Reading
22 - Final TSC Meeting
23 - Bill 65 - 2nd Reading
28 - Castlegar - Family Info Night
29 - Vernon - Family Info Night
30 - Prince George - Family Info Night

Several people who were interviewed also expressed appreciation for the fact that knowledgeable experts were brought into the picture to inform the work of the TSC.

3. Solidarity

A limitation of the TSC process was that some of the initial community enthusiasm and mobilization abated. However, several people who took part in the research indicated that the voice of the community living movement nonetheless became stronger and more unified, in part because the Coalition and TSC process served as rallying points. The increased solidarity and common understanding of the issues can in turn be harnessed for addressing emerging issues.

Particularly under the Community Living Coalition, it was reported that families came to share a common vision, a sense of connectedness and an ethos of mutual assistance – of neighbours helping neighbours. This feeling is reportedly growing. Said one respondent, "There is less a sense of 'what I can get out' and more of a sense of 'how I can help' ". That attitude reportedly seeped into the operating culture of the Interim Authority.

As well, there is a reported increase in solidarity between service providers and families, in part because they are more likely to be pursuing a similar vision now than previously.

4. Financial

a. Cushioning the Impacts

Several people who were interviewed commented that, owing in part to the work of the TSC and Community Living Coalition, some of the money slated to be taken out of the community living services system had been safeguarded. The cuts were not on the same order of magnitude as they were for services to children and families. Major cuts that were originally slated to come into effect in fiscal 2003-04 were forestalled to 2004-05. Said one respondent, "There was no question that the government was going to cut back and had already made very serious cut backs. They would have been a lot more blunt if we didn't get in the room and address the issue."

Further, the people involved at the TSC table were able to present a convincing case that one-time transitional funding would be required to address system change efforts; the government built an additional $47 million into the provincial budget of 2002-2003 for that purpose.

b. Increased Efficiencies

In some agencies, many more people are reportedly getting services now than a few years ago. In part this increased service efficiency was attributed to service providers voluntarily implementing the vision of more flexible and cost-effective supports that underlay the work of the Coalition and the TSC.

c. Securing of Investments for Community Development

Investment in community development was important to furthering the work of the Coalition and the TSC. Project funding that the BCACL federation had been able to secure made it possible to assist many families to come to meetings, conduct community forums, reflect on and discuss developments in the sector. The Individualized Funding Family Coalition received money from the VanCity Community Foundation and the Vancouver Foundation that helped to fund leadership development forums around Individualized Funding, which in turn were linked to the broad vision of a new system and the community mobilization process. Foundation money was also available for the communications work of the Community Living Coalition and supported people to travel to the lower mainland from other regions of the province to participate in meetings.

5. Realism

Overall, the Coalition and TSC took a realistic view of the operating context, capitalized on opportunities and strategic necessity, and furthered their working relationships with government.

a. Pragmatic Grasp of the Operating Context

Before the TSC was established, the government had been operating for years in the context of fiscal constraints (e.g., recession of the early 1990s, reduced federal transfers in the mid-1990s, weakened economy in the late 1990s, ordinary people's 'tax fatigue') and political imperatives (e.g., to safeguard vulnerable children) that hampered its ability to funnel as much money into the seemingly insatiable needs of the community living system as family members, self-advocates, other advocates and service providers – and perhaps the government itself – may have wanted. The fiscal pressures came to a head in fiscal 2001-2002 and arguably *did* require decisive spending restraint measures on the part of the government. It was recognized by the Coalition and TSC that any efforts to bring about system change had to be framed and realistically carried out in that context.

While for some people the pace of the TSC's work was alienating, several other people who were interviewed indicated that the fast pace of the TSC's work, and that of the Interim Authority, was deliberate. On the one hand, an aim was to keep at least one step ahead of government and to have thought through in advance the questions and issues that the government was likely to raise. On the other, it was reasoned that the likelihood was slim that the government would make any major decisions in the year prior to the election of 2005. As the window of opportunity was likely to close some time in the spring of 2004, it was important to move things forward as quickly as possible in 2002 and 2003.

As well, the government had signalled through its Core Services Review, budgetary decisions and the MCFD *Service Plan* that major changes were imminent. MCFD had itself accepted the position that incrementalism and "tinkering" were not options and was moving forward on the basis of radical change.[164] Coalition and TSC members generally felt that incremental approaches didn't stand much of a chance in the then-present policy environment. If those who sided with incremental approaches tended to feel alienated from the TSC's work and from the broader system change process, it is difficult to see what other tack the Coalition and TSC could have realistically taken at the time.

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[164] See the MCFD *Discussion Paper on Community Living Services*, p. 5.

b. Capitalizing on Opportunities and Strategic Necessity

The major sea changes in the policy and program landscape that began rolling out in 2001-2002 presented very serious challenges and potential threats to the well being of people with developmental disabilities and their families. The government was moving forward with those and other changes on the basis of an overwhelming majority at the polls, a clear mandate to do things differently in the province and a marginalized opposition in the Legislative Assembly. However, the impending changes also presented opportunities to restructure a system that had become highly restrictive, inflexible, unsustainable and even dysfunctional in its present form. Community leadership emerged that saw the value of engaging with the government and in capitalizing on the opportunities rather than to trying to stop what was, in the short term at least, an irresistible force.

While some of the leadership among people who coalesced around individualized funding (the IFFC) and around community governance had been somewhat mistrustful of one another and did not agree on various points, they saw the strategic necessity of 'burying the hatchet', finding points they could agree upon and of moving forward together on that basis.

Even though family members and other community advocates had misgivings about service providers, they made intentional efforts to reach out to, engage with and find points of common interest with service providers who shared common values and who had their own concerns about the *status quo* and about the emerging policy and program situation. For their part, some service providers who saw the need for system change, and who had decided to focus on the emerging opportunities and possibilities instead of the dangers and risks, recognized the strategic value of joining forces with family members and other advocates who shared similar values and perspectives.

A diversity of other family, disability-specific and service organizations that had disparate interests and mandates saw the strategic necessity of sinking their incidental differences and of coming together to hammer out a broadly-based consensus approach to system change that would be community-led in partnership with the government.

c. Working Relations with Government

For one respondent, a key lesson learned throughout the course of the TSC's work was the need for the community to have a working relationship with government. The respondent said, "Previously, you shamed the NDP in the media to get what you wanted. It's hard to have relationship with the Minister and Deputy Minister who are about to gut programs, but this is how you get your phone calls answered."

As well, several of the people on the TSC had prior relationships with people in government, which yielded senior level reconnaissance about emerging opportunities and pressure points. While these relationships became more difficult to maintain, they were credited with the Coalition and TSC being able to move their agenda forward.

6. Vision

Throughout the TSC process, a consistency of vision and several key ideas were upheld.

a. Consistency

The TSC built upon the Coalition's earlier report and there are many underlying similarities. Modifications were made by the TSC with a view to achieving a broader level of consensus. Said one respondent, "Good strong vision held the day."

The point of constancy of vision was again raised at the table of the Interim Authority in the fall of 2003. Overall, people who were at the Interim Authority table felt that the basic vision that informed their work continued to be based on the work of the Coalition and the TSC.

b. Key Concepts Upheld

While perhaps challenging from an operational point of view, and not fully spelled out in detail in the TSC report, the key concepts of community governance, individualized funding and autonomous planning support were key features in the document. As well, there was recognition that people needed to be embedded in their communities in order to have a reasonable chance of safety, security and quality of life.

7. Broad-level Support for Overall Critique, Vision and Direction

Families, service providers and some government officials came to a common understanding of the challenges and problems that beset the community living services system, although each tended to accord different emphasis to particular issues. That understanding came about over the years as a result of dialogues and discussion between the stakeholders and was reflected in the work of the TSC.

These stakeholders also came to a common view of some of the potential solutions to the problems and challenges, which again was reflected in the work of the TSC.

The dialogues, discussion and the evolution of common views required a basic measure of mutual respect and trust among stakeholders. While such trust could perhaps have been more pervasive, it was cultivated to a significant degree before and during the TSC process.

Even the critiques of groups like the government-appointed Evaluation Committee, the BCGEU and Family Partners took issue not so much with the TSC's general principles and directions but more on the details and pace of moving system reforms forward.

8. A Community-Led Interim Authority for Community Living was Established

While not all would herald the establishment of the Interim Authority for Community Living as an unqualified success, the work of the TSC did lead to this outcome. Family members of people with developmental disabilities comprised 18 of its 24 member Board. Self-advocates comprised another three members.

If the Board of the Interim Authority was not fully representative of all families' and self-advocates' perspectives in the province, it was arguably more representative and inclusive of family and individual voices than previous governance arrangements for community living services.

C. Further Considerations

Hindsight is twenty-twenty and there is always a risk of presenting simplistic solutions for complex problems. However, on reflection several key "lessons" do emerge from the research that could guide the future efforts of stakeholders in the well-being of people with developmental disabilities in BC. First, it seems reasonable that people considering any replication or continuation of the TSC process would continue doing the actions that contributed to the strengths of the process (above). Second, if greater attention had been paid to the following considerations during and after the work of the TSC, some of the opposition and other difficulties could perhaps have been averted and allayed.

1. Building on Shared Values

A coherent set of values has emerged in the community living sector in BC that enjoys broadly based support and that can be built upon. These values include, among other things:

- dignity and respect for individuals regardless of the nature or severity of disability;
- dignity and respect for the families of people with disabilities;
- individualized and responsive approaches to meeting people's support requirements;
- system and program flexibility to adapt and modify supports as people's changing needs warrant;

- portability of supports across life situations and across regions of the province;
- substantive consumer say and control in service arrangements and in determining their own life course and solutions to the problems they face;
- ensuring people's basic safety and well-being in the context of reasonable risk-taking and chances for a good life in the community;
- the full inclusion and participation of people with developmental and other disabilities as valued, contributing citizens in the relationships and broader social fabric of their communities; and
- community and government responsibility to assist individuals and families to secure, in ways that are fiscally sustainable, the supports needed for inclusion and participation in society.

In the interviews and focus groups that were conducted for the research we did not hear any serious disputing of these basic values. Arguably, it makes sense for stakeholders to keep one eye trained on the underlying values that bind them together in common purpose rather than getting too embroiled in contentious discussions on practical means to ends, over which they may disagree in the near term and that can strain amicable working relations over the longer term.

2. Maintaining Bold Vision while Conserving and Extending the Present Good

Some of the difficulties could have been avoided if a workable balance had been struck between, on the one hand, audacious vision and forward-thinking and, on the other, the familiar arrangements that people presently value because they consider the arrangements to be working reasonably well for themselves. Audacious vision and creative thinking are not necessarily at odds with the present good and incremental improvements.

3. Including Diverse Stakeholders, Experiences and Perspectives while Upholding Principles

In a healthy democracy, the policy and program change process would ideally be structured so that the people who will be affected by its outcomes feel that they have a direct stake and say in charting the direction – that they have some ownership of the process and its results. If the TSC represented an attempt by government to involve family caregivers and self advocates in the system change process, the process was not inclusive enough for some people. Addressing this issue would likely have involved slowing the process down, opening the process up for more dialogue and collaborative problem solving, and providing for the differentiation of solutions so that these accord with local needs and preferences.

Similarly, it would have been helpful if stakeholders had found ways of being more open to the experiences, ideas and concerns of one another, even where those experiences, ideas and concerns sometimes seemed inappropriate or dissonant. Such viewpoints would have to be addressed one way or another, either from within the reform process or from outside the process, demanding the attention that was due.

At the same time it would have been important to safeguard over-arching principles and standards of quality to which everyone needed to be held accountable.

4. Acknowledging and Engaging Diverse Talent

While the TSC did invite input from knowledgeable experts, there was arguably a wealth of expertise within the community living sector in BC that could have been better harnessed to address various operational issues. This may have meant engaging in issue identification and solution development a greater diversity of family members and self-advocates, or government officials and other professionals with the necessary skills and experience.

5. Addressing Questions and Concerns

It was pointed out in a few interviews that the TSC would have sent positive messages if members who didn't know the answers to questions would have been more ready to admit the fact, and would have committed to finding out and to getting back with answers or proposed solutions in a timely way.

By inference, if there were no self-evident answers or solutions, TSC members would ideally have engaged the questioners as allies in joint fact-finding, brainstorming and problem solving.

6. Doing the Needed Technical Work

Detailed technical work was needed to:

- develop reasonably fair and fiscally sustainable approaches to resource allocation (i.e., addressing the "who gets what and on what basis" issue);
- facilitate the "unbundling" of traditional funding and service approaches while safeguarding the well-being of people whose funding and services are not being unbundled; and to
- develop community willingness and capacity to involve and support people with intellectual disabilities in ways that reduce their reliance on formal services while at the same time ensuring that the community continues to acknowledge and make provision for the services that will be needed.

People wrestling with such practical issues were looking for a clearer sense of how they would be addressed in the new system.

7. Setting Reasonable Limits

It would have been helpful if stakeholders – both community members and government officials – were clearer about what they could and could not realistically deliver, and about the matters on which they were uncertain. Ideally the stakeholders would have continued to work to deliver what they realistically could while avoiding the impression that was left in many people's minds that government and community leaders were making promises that couldn't be kept. That impression resulted in diminished confidence in the reform process and even mistrust and disillusionment.

XIII. Summary

The BC Liberals came to power in a crushing landslide victory in May 2001. The new government moved forward with an aggressive agenda that included major fiscal restraint and the devolution of some key responsibilities from government to other authorities.

The Core Services Review, Ministry Service Plans and budgetary responses to the looming provincial deficit spurred family members, other community activists and service providers into action. While the government's intended directions presented dangers and risks to people with developmental disabilities and their families, activists recognized that there were new opportunities to reform a community living services system that was in crisis and unsustainable.

The post-institutional era of plenty for that system was over. There was little new money for community living services, yet the demand for service continued to escalate year over year. Funding was channelled mainly to issues of child protection and the most serious cases of health and safety. Per person costs were high and in some cases astronomical; average per person costs approached $60,000 per year and in some cases were three to five times higher. People with similar needs received dissimilar levels of funding and service. Many received nothing at all and the wait lists were growing. While there were demands to increase the level of funding for traditional services, there were new demands for more individualized approaches and funding models.

People were asking serious questions about the appropriateness and responsiveness of the services available. Not all held favourable views of government social workers, who increasingly functioned as gatekeepers to a highly restrictive system; other social workers who were making a positive difference were not always recognized for their efforts. Many people felt that they didn't have much control or say in the system. Different understandings of disability vied for attention and different understandings of the best mix of supports – formal and informal, agency-based and individually directed – competed across rural and urban communities. Services needed across the lifespan and across life situations were not well coordinated and typically lacked portability from one part of the province to the next. Government procedures were inflexible and organized labour had come into unprecedented power and control in the system. Wage settlements reached at the end of the previous government's regime meant service levels that would have to be reduced if managers were to live within budgets. In the balance many families felt fearful about losing their hard won gains, alienated and even entirely shut out of the system.

While change was needed, not all saw eye-to-eye on what a new set of arrangements should look like.

Some stakeholders in the community recognized the strategic importance of moving beyond their incidental differences of opinion and mutual mistrust towards a consensus-based approach to a new policy and program model. The new approach was to be community led and operationalized in partnership with government. They began talking in earnest with one another about a radical new initiative that would be framed as one to help government wrestle greater efficiencies from limited resources thereby reducing the growing wait lists, while at the same time affording greater flexibility, responsiveness, portability, choice, control, social inclusion and ultimately satisfaction for the users of the services provided.

Community members fashioned various proposals around those themes and ultimately came together in an unprecedented show of solidarity in the Community Living Coalition. The Coalition was able to persuade the government that the proposal it tabled enjoyed broadly based support and was the map for setting the future course of community living services in the province.

The Coalition secured the resources and mandate from government to work together with government officials in a Transition Steering Committee. That committee was to develop recommendations for the Minister of MCFD on governance, resources and other arrangements that were needed to give further detail to the general map that the Coalition had developed. The TSC intended that an Interim Authority for Community Living would develop still further details, as would a fully constituted Authority for Community Living that was to operate at arm's length from government.

The TSC completed an enormous volume of work in a short space of time that required thousands of hours of volunteer effort.

The scope of the TSC's work was impressive, covering topics such as community-based governance, citizenship and choice, accountability and transparency, safety and well-being and various organizational and financial implications of the proposed new system. The latter included not only transitional funding but the re-allocation of the present human resource complement at MCFD and other human resource implications. The document also dealt with limiting the future costs to government and to the new Authority through innovation and increased productivity, and by recouping revenue through the sale of selected assets.

In its work, the TSC synthesized and refined the work that had preceded, including the early pioneering efforts of the Community Living Society on individualized funding and independent planning supports and the further articulations of those ideas that occurred at various symposia and summits that were held from 1997 to 2000. The TSC synthesized within its report the "Framework Document" of the Individualized Funding Family Coalition, the "Community Governance Proposal" of the Community Living Coalition and various other documents that were generated by service providers and other groups and individuals, including the work of a provincial Joint Committee that represented diverse organizations.

All the while the TSC attended to matters such as draft legislation for the Interim Authority, impacts of other legislation concerning employment and social assistance for people with developmental disabilities, tax implications of new financing arrangements, the transition of young people to the system of services for adults, safeguards for people currently in the community living system, inter-ministerial linkages and Treasury Board's eleventh hour determination that savings could not be carried over from one fiscal year to the next for re-investment in direct services to deal with burgeoning wait lists.

Thirty-two individuals and organizations in BC provided written feedback on the work of the TSC. In terms of the broad directions set out in the TSC's report, the government-appointed Evaluation Committee, the British Columbia Government Employee and Service Union (BCGEU) and Family Partners were generally supportive. However, each of these groups had concerns about the lack of detail on important issues.

These included, among other things, the likely service delivery outcomes of the proposed arrangements, the actual scope and authority of the Minister of MCFD to bring about the proposed changes, implications of increased community responsibilities and service reforms in the context of government budget and service cuts, responsiveness to planning and service needs in rural communities, job security and the adequacy of workers' pay, details on how to address wait lists, and community representation in any future system design and implementation arrangements. Those critiques also surfaced in the interviews conducted for the research.

Further issues were the fast paced agenda of the TSC and of the broader system reform process, the TSC's backing of a radical new approach rather than slower-paced, incremental changes and the need to secure and maintain broad level "buy in".

"Buy in" was compromised by the perceived insularity of the TSC and by a community outreach strategy that would ideally have been more robust, more welcoming of and responsive to community input, and that would have built on community momentum to develop a more responsive and workable system. There were the further challenges of keeping government informed and onside both during and after the TSC's work, clarifying whether families actually drove the TSC, and dealing with the issue of whether and which families would ultimately have say in decision making about eligibility and resource allocation for community living. Technical details such as resource allocation principles and results indicators needed further work, and concerns lingered about the perceived lack of operational depth at the TSC table and the necessity of separating funding and planning functions.

The TSC's work would likely have been strengthened if greater recognition and attention had been given to the underlying values that people held in common, despite differences of opinion on practical matters. As well, the process would ideally have been structured to allow broader input and say for people who would be directly affected by system change. Questions and concerns arising from the community would have been addressed in a timely way and more progress would have been made in sorting out some challenging technical issues on resource allocation, administration of service dollars and community development. As well, stakeholders would have avoided leaving the impression that they could deliver more than was actually the case.

On a more positive note, the TSC built upon years of pioneering work by families so in that sense was driven by the contributions of families to system reforms. Although initially tense, TSC meetings and committee work became amicable and highly productive in a short period of time. If community solidarity and cohesion required further attention, the TSC served as a rallying point that contributed to a strengthening of community cohesion and an ethos of mutual assistance. The TSC helped lessen the adverse impacts of budget cuts and generated and gave further voice to ideas that service providers used in their efforts to achieve greater efficiencies and service responsiveness. For their part, some member organizations within the Community Living Coalition managed to secure additional funding to bring people together to discuss concerns and possibilities, which in turn fed into the work of the TSC.

The leadership within the Community Living Coalition and the TSC took a pragmatic approach to "sizing up" the policy and program context and made deliberate choices to capitalize on opportunities and to respond to strategic necessities. While relationships with government could perhaps have been more diligently cultivated and maintained, the Coalition and TSC for the most part opted to work in partnership with government instead of taking an adversarial stance that was unlikely to yield positive results.

The TSC built on the vision for community living that lay at the base of its inception and developed a document that continued beyond the lifespan of the TSC to inform the work of the Interim Authority for Community Living British Columbia.

That there was an Interim Authority consisting mainly of family members and self-advocates, and that there continues to be a plan for a fully constituted Authority for community living at arm's length from government, is in no small measure the result of the TSC's work.